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Award Number: DAMD17-02-1-0658

TITLE: Parkinson's Action Network Public Policy Forum

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Christy Hahn

CONTRACTING ORGANIZATION: Parkinson's Action Network
Alexandria, Virginia 22314

REPORT DATE: December 2002

TYPE OF REPORT: Final

PREPARED FOR: U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

DISTRIBUTION STATEMENT: Approved for Public Release;
Distribution Unlimited

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20030317 053

REPORT DOCUMENTATION PAGEForm Approved
OMB No. 074-0188

Public reporting burden for this collection of information is estimated to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing this collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to Washington Headquarters Services, Directorate for Information Operations and Reports, 1215 Jefferson Davis Highway, Suite 1204, Arlington, VA 22202-4302, and to the Office of Management and Budget, Paperwork Reduction Project (0704-0188), Washington, DC 20503

1. AGENCY USE ONLY (Leave blank)		2. REPORT DATE December 2002	3. REPORT TYPE AND DATES COVERED Final (1 Mar 02 - 30 Nov 02)	
4. TITLE AND SUBTITLE Parkinson's Action Network Public Policy Forum			5. FUNDING NUMBERS DAMD17-02-1-0658	
6. AUTHOR(S) : John Rodgers Christy Hahn				
7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES) Parkinson's Action Network Alexandria, Virginia 22314 Email: chahn@parkinsonsaction.org			8. PERFORMING ORGANIZATION REPORT NUMBER	
9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES) U.S. Army Medical Research and Materiel Command Fort Detrick, Maryland 21702-5012			10. SPONSORING / MONITORING AGENCY REPORT NUMBER	
11. SUPPLEMENTARY NOTES				
12a. DISTRIBUTION / AVAILABILITY STATEMENT Approved for Public Release; Distribution Unlimited				12b. DISTRIBUTION CODE
13. Abstract (Maximum 200 Words) (abstract should contain no proprietary or confidential information) <u>Forum Objectives and Program:</u> The Science and Research Forum will serve as a premier educational program for Parkinson's patients and researchers. The primary goal is to bring together participants in order to share information and learn about the latest developments in Parkinson's research. Through plenary sessions, workshops and networking opportunities, participants will learn about the latest research and discuss creative ideas for new research endeavors. Fundamental to the success of the Forum is the premise that visiting scientists and researchers can learn from each other and from Parkinson's patients and caregivers. A number of prominent scientists and representatives of Federal agencies engaged in Parkinson's-related research will provide a definitive summary of the "State of Parkinson's Scientific Research." The presentations will summarize the status of ongoing research, discuss newly-released data, and address the regulatory approval processes that allow therapeutic breakthroughs to reach patients. <u>Follow-up Report:</u> Following the Science and Research Forum, PAN will provide the USAMRMC with a detailed written report summarizing the presentations and recommendations generated by the ensuing discussions. <u>Funding Request:</u> PAN's funding request remains at the same level \$40,000 level specified in the November 20, 2002 letter to Dr. Stephen Grate at USAMRMC. The only amendment is that these funds are to be devoted exclusively to support of the Science and Research Forum.				
14. SUBJECT TERMS: Parkinson's Disease			15. NUMBER OF PAGES 102	
			16. PRICE CODE	
17. SECURITY CLASSIFICATION OF REPORT Unclassified	18. SECURITY CLASSIFICATION OF THIS PAGE Unclassified	19. SECURITY CLASSIFICATION OF ABSTRACT Unclassified	20. LIMITATION OF ABSTRACT Unlimited	

Parkinson's
Action
Network

2002 Public Policy Forum Sponsors

The Edmond J. Safra Philanthropic Foundation

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*Morton Kondracke's book, Saving Milly, is made possible for Forum attendees
by a generous gift from the Vivian and Charles Sukenik Philanthropic Fund.*

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Parkinson's Action Network

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Dear Parkinson's Advocate:

Welcome! We know that with your help, we will make the 8th Annual Public Policy Forum the most successful yet. Whether this is your first or your eighth Forum, by being here today, each and every one of you plays an important role in "Fighting for a Cure."

This year is especially exciting – in addition to the events we have scheduled for the Forum, a Parkinson's-related Hearing before the Senate Appropriations Subcommittee will also take place on Wednesday morning, May 22. Michael J. Fox, Mohammad and Lonnie Ali and PAN President, Joan Samuelson will be testifying. We hope you will stay for this hearing, as it is another great way to show your support and help raise the profile of the Parkinson's community.

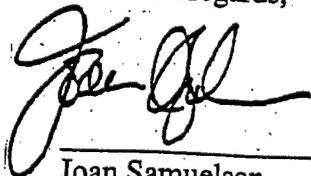
During the next three days, you will learn about the most recent scientific breakthroughs in Parkinson's research directly from members of the scientific community. You will receive training and information to help you deliver a powerful message to Congress – that Parkinson's disease can be cured if the financial resources are committed to match the research opportunity. Most importantly, you will share experiences with dedicated advocates like yourself, who know the daily struggle of Parkinson's and choose to make the fight public.

The Public Policy Forum is an informative, productive, and above all, fun three days. It is an excellent opportunity for the whole Parkinson's community to join forces toward our common goal – finding a cure for Parkinson's disease.

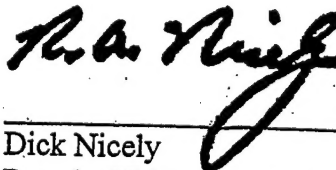
Many of you have traveled across the country to be here today, and we thank you for your commitment to our mutual cause. We hope that you enjoy your stay in Washington and take advantage of this opportunity to meet some wonderful new people.

Get ready to take action and make a difference!

Warmest regards,



Joan Samuelson
President



Dick Nicely
Board of Directors, Chair



EIGHTH ANNUAL PUBLIC POLICY FORUM

"FIGHTING FOR A CURE"

May 19-21, 2002

**Holiday Inn
415 New Jersey Ave., NW
Washington, D.C. 20001
On Capitol Hill**

Saturday: May 18

2:00 – 6:00 pm

Early Registration at the Hotel (Prefunction space)
Briefing books and schedules to be provided

Sunday: May 19, Day 1

8:30 – 9:00 am

Registration at Hotel (Prefunction space)
Briefing books and schedules to be provided

9:00 – 10:00 am

Meet and Greet at Continental Breakfast
(Prefunction space)
Forum Participants introduce themselves

10:00 – 10:30 am

Welcome and Introduction of PAN Officers
(Federal North)
Provide overview of our strategies and goals
Joan Samuelson, President; Elisabeth Bresee Brittin,
Executive Director; John Rogers, Education and
Advocacy Director; Laura Eckart, Deputy Education and
Advocacy Director

10:30 – 11:30 am

Plenary Session: Grassroots Advocacy Program
(Federal North)
Need, Value and Functions of Grassroots Advocacy
Overview of new State/Congressional Coordinator
Initiative
Appropriations

Other Legislative efforts of PAN web site, software and its functions
Overview Regenerative Medicine (embryonic stem cells, therapeutic cloning.)
John Rogers and Laura Eckart

11:30 – 12:00 am

Break

12:00 – 1:00 pm

Box Lunch (Prefunction space, Federal North)
Keynote speaker: Morton Kondracke, PAN Board Member, Journalist and Author
Introduction by: Michael Claeys (The Michael J. Fox Foundation For Parkinson's Research)
History of Advocacy
Hand out paperback of "Saving Milly"

1:00 – 2:00 pm

Advocacy Training Sessions:

1. **Washington 101: Overview of the Political Process** (Federal North)
(Undergraduate course) -recommended for new Forum participants
Moderator: Elisabeth Bresee Brittin
Panel: Laura Eckart (PAN)
Ed Long (Capitol Associates, Inc.)
Michael Claeys (The Michael J. Fox Foundation For Parkinson's Research)
Robert Boorstin (Greenberg Quinlan Rosner Research, Inc.)
Lynn Fielder (Planned Parenthood)
30 minutes for Q&A
2. **Strategically Expanding the Base** (Congressional Room)
(Graduate course) -recommended for previous Forum participants
Moderator: John Rogers
Panel:
Daniel Weiss (M&R Strategic Services)
Gail Pressburg (Institute for Civil Society)
Dr. Patricia Hawkins, PhD (The Whitman Walker Clinic)
Ronnie Tepp (Juvenile Diabetes Research Foundation)
20 minutes for Q&A

2:00 – 2:30 pm

Break

2:30 – 3:30 pm

1. Yoga session (Judicial and Executive Rooms)

**2. Lessons From the Field: Discussions by
Experienced Advocates (Federal North)**

(Graduate course)

Moderator: John Rogers

Panel: Greg Wasson, Bill Franklin, Perry Cohen, Ann -
Jeannette Campbell

3:30 - 4:45 pm

Break

4:45 - 5:45 pm

Neuroprotection Initiative at NINDS (Federal North)

Moderator: Jeffrey Martin, Esq. (PAN Board Member)

Panel:

Dr. John Marler (NINDS), Dr. Bernard Ravina
(NINDS), Dr. Karl Keiburtz (University of Rochester
Medical Center), Dr. Ross Stein (Brigham and Women's
Hospital)

5:45 - 7:00 pm

Reception at Hotel (Federal South)

Cash Bar and light food

Forum Participants will provide their own dinner.

Monday: May 20, Day 2

8:00 - 9:00 am

Continental Breakfast (Prefunction space)

9:30 - 10:00 am

Joan Samuelson, President, PAN (Federal North)

Importance of PAN and Patient's Rights Groups

10:00 - 11:15 am

**Federal Programs Funding Parkinson's Research
(Federal North)**

Moderator: John Rogers, PAN

Panel:

Terrell Halaska, Deputy Chief of Staff, Office of
Secretary Thompson, HHS

Dr. Diane Murphy, Program Director, National Institute
of Neurological Disorders and Stroke

Dr. Cindy Lawler, National Institute for Environmental
Health Sciences

Lt. Col. Karl Friedl, Department of Defense; Neurotoxin
Exposure Treatment Research Program

11:15 - 11:45 am

Break

11:45 - 12:35 pm

Plenary Session Part I: (Federal North)

Introduction/Moderator: Elisabeth Brittin, PAN

Panel discussion of latest drug therapies for Parkinson's

Representatives from Pharmaceutical Corporations

GlaxoSmithKline, Dr. Linda Sigmund- "Requip"

Schwarz BioSciences, Dr. Joseph Bianchine, M.D.,

Ph.D.- Dopamine agonist patch

Teva Neuroscience, Dr. Phyllis Salzman, Ph.D.-
Etilevodopa, Rasagiline
15 minutes for Q&A

12:35 – 12:45 pm

Box Lunch

Pick up lunch and return to Plenary Session Part II

12:45 -1:30 pm

Plenary Session Part II: (Federal North)

Panel discussion of latest drug therapies for Parkinson's
Amersham Health, Dr. David Brooks, M.D.- What Brain
Imaging Can Offer Parkinson's Disease
Titan Pharmaceuticals, Dr. Roy Bakay- Spheramine
therapy
10 minutes for Q&A

1:30 –2:00 pm

Break

2:00-3:30 pm

Plenary Session: (Federal North)

Panel Discussion with Hill and PAN Staff

**Washington 2002: What to Expect including Role-
Playing Exercises**

Moderator: Laura Eckart

Panel:

John Rogers- Education and Advocacy Director, PAN
Alan Macleod -CoS, Rep. Ron Kind, D-WI
Robin Bachman- LD, Rep. Carolyn Maloney, D-NY
Jessica Robinson- LA, Rep. Lane Evans, D-IL
Melissa Busse- LA, Rep. Joe Skeen, R-NM
Tricia Brooks- Coalition for the Advancement of
Medical Research

3:30 – 4:00 pm

Break

4:00 – 5:00 pm

**Regional Teams to meet to develop and coordinate
plan for next day Hill visits.**

Tuesday: May 21, Day 3

8:00 am

Continental Breakfast (Prefunction space)

8:30 am

Start boarding bus to Hill

8:45 am

Depart for the Hill

8:50 am

Buses arrive on Capitol Hill

9:00 – 9:30 am

Group picture on the Hill

10:00 – 11:15 am

Scientific Briefing

216 Hart Senate Office Building

[Hill Members and Staff invited]

Senator Paul Wellstone, (D-MN)

Introduction by Joan Samuelson, PAN President

Panel:

Dr. Deborah Cory-Slechta, MD, PhD, University of Rochester

Dr. Jeff Kordower, PhD, Rush Presbyterian Medical Center

Dr. John Gearhart, MD, Johns Hopkins Hospital

11:15 – 11:30 am

Break

11:30 – 1:00 pm

Box Lunch (on the Hill)

1:00 – 4:00 pm

Visits on the Hill

PAN Staff location: Longworth Cafeteria on the House side and Dirksen Cafeteria on the Senate side

3:00 pm

First bus departs from Hill to Hotel

4:00 pm

Last Bus departs from Hill to Hotel

6:30 pm

Udall Awards Dinner

Capital Hilton

1001 16th Street, NW

Washington, DC 20036

Wednesday, May 22, Day 4

7:30 am

Continental Breakfast at Hotel

8:00 am

Begin boarding buses for the Hill

8:15 am

Depart Hotel for the Hill

8:30 am

Arrive Capitol Hill

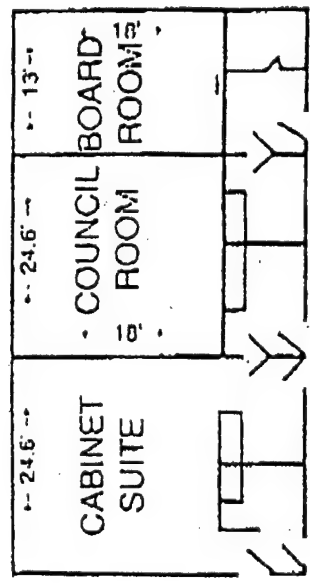
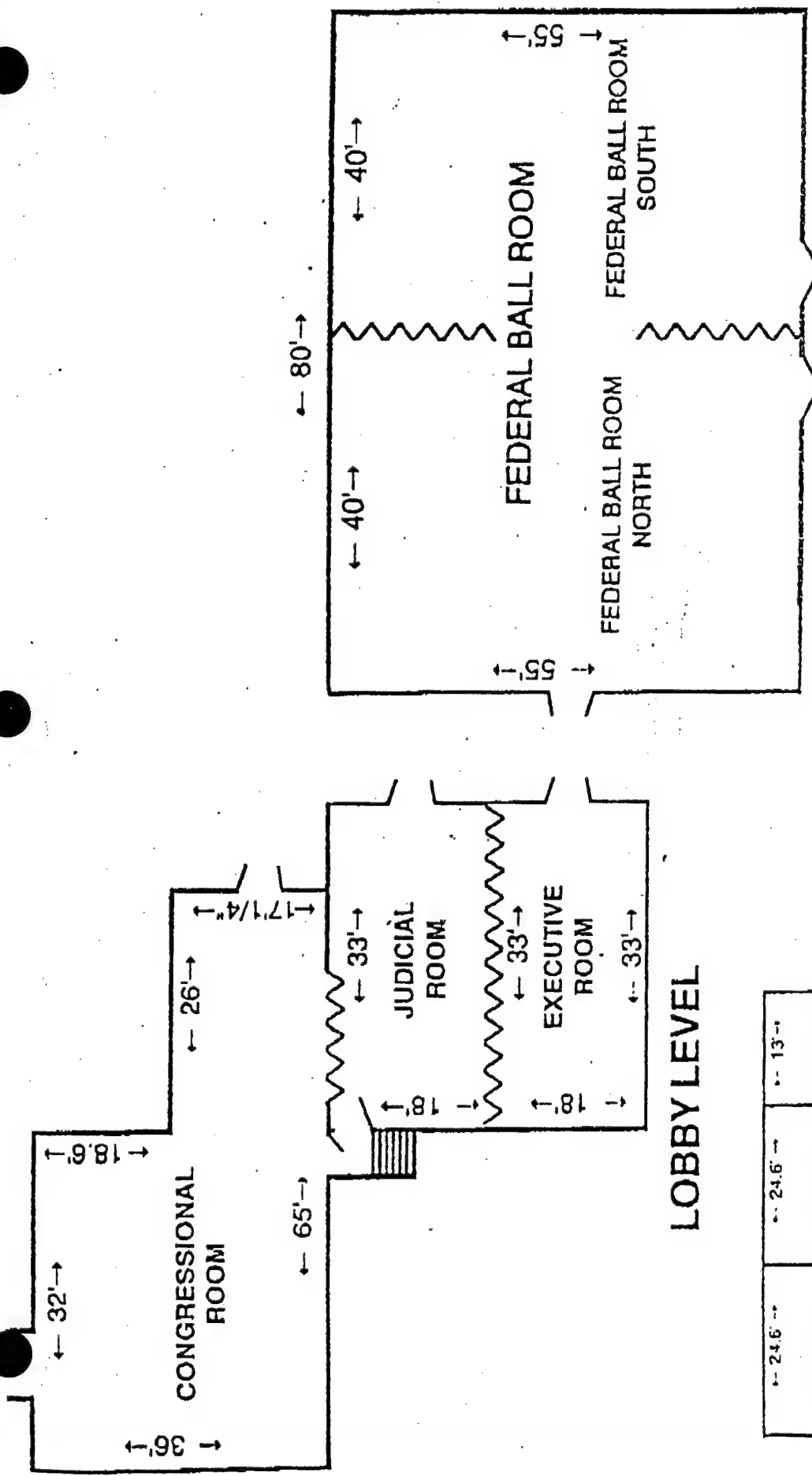
9:30 am

Senate Appropriations Subcommittee on Labor, Health and Human Services and Education Hearing

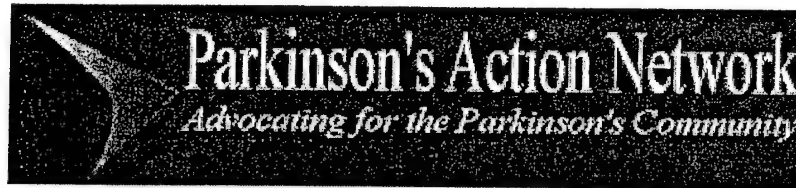
216 Hart Senate Office Building

Noon

**Buses depart Capitol Hill for Hotel
Shuttle leaves every half hour**



Washington, DC on The Hill



PAN Mission Statement

The Parkinson's Action Network (PAN) is the unified advocacy voice of the Parkinson's community, fighting for a cure within five years. Through education and interaction with the Parkinson's community, scientists, policy and opinion leaders, and the public at large, PAN advocates for increased and accelerated investment of public resources to ease the burden and bring a cure to the million Americans who suffer from Parkinson's.

History & Accomplishments

Parkinson's Action Network was founded in 1991 and has made great strides in a short amount of time to increase public awareness of the disease and to educate Congress about the need for federal research funding.

Over the last ten years, PAN has led advocacy efforts for the Parkinson's community and has been at the forefront of the fight for an increased investment in biomedical research at the National Institutes of Health (NIH), the Department of Defense (DoD) and the Department of Veterans Affairs. PAN has been instrumental in educating Congress, the Administration and the public about Parkinson's disease, the state of current research and the need for a greater investment in research to keep in pace with scientific potential.

Furthermore, PAN has invested a great deal of time and devoted significant resources to empowering the Parkinson's community and developing an effective grassroots network of advocates across the country.

Among PAN's Most Significant Accomplishments Are:

- **Parkinson's Disease Research Agenda:** Based on PAN's successful advocacy efforts, in 1999, Congress directed the NIH to develop the first ever Parkinson's research agenda, which detailed a Five-Year Research Agenda and funding plan. The plan called for a \$1 billion investment in Parkinson's research over five years. The FY 2002 Labor-HHS Appropriations bill contained unprecedented language directing the NIH to fully fund the Parkinson's Disease Research Agenda.
- **Stem Cell Research:** In 2001, played a major role in persuading the Bush Administration to allow – for the first time ever – limited federal funding for embryonic stem cell research. PAN President Joan Samuelson's testimony before a House Committee, along with outstanding assistance from our grassroots community, and media appearances by PAN, had a tremendous impact on the debate.

- **Morris K. Udall Parkinson's Research Act of 1997:** Led the effort to enact this groundbreaking legislation – the first ever to focus entirely on the need to expand the Parkinson's research program administered by the NIH– calls for at least \$100 million in Parkinson's-focused research, Eleven Udall Research Centers and awards for innovative research.
- **DoD Parkinson's Program:** Secured funding increases for the Department of Defense Neurotoxin Exposure Treatment Research Program which is attempting to determine the cause of Parkinson's in the course of finding ways to defend against chemical warfare. The FY 2002 Defense Appropriations bill contained \$17 million in funding for the program, a \$2 million increase over 2001.
- **VA Parkinson's Centers:** Played a key role in supporting the Department of Veterans Affairs "Parkinson's Disease Research, Educational and Clinical Centers." More than \$30 million has been allocated over four years for these six new centers which will be specialized in Parkinson's research, education and clinical care.
- **Public Policy Forum:** Established an annual Advocacy Training Forum in Washington, DC to train men and women from across the country to become informed, active and effective advocates in the fight for a Parkinson's cure.
- **Capitol Hill Press Conference:** Held a press conference with Congressional supporters to focus media attention on the lack of sufficient funding for Parkinson's-focused research at the NIH. Released scientific study of National Institute of Neurological Disorders and Stroke (NINDS) Parkinson's research grants, showing that the institute over-stated what it reported spending on Parkinson's-focused research.
- **Scientific Briefings:** Bring together leading Parkinson's researchers to brief Congressional supporters on recent scientific advances and breakthroughs.
- **Fetal Tissue Research:** Played a leading role in the successful effort in the early 1990's to lift the Congressional ban on fetal tissue transplantation research. The NIH now supports several fetal tissue clinical trials, and preliminary results continue to show promise.



Parkinson's Action Network's Goals:

Research: Strengthen the Parkinson's research program, through increased federal funding and coordinating efforts by the several Parkinson's-related institutes of the National Institutes of Health with those in the private sector.

Awareness: Increase public awareness of Parkinson's disease and its impact on individuals, health costs, and the country as a whole.

Education: Inform Congress and the Administration—directly and through grassroots advocacy—of the needs and the impact of their decision-making on the Parkinson's community.

Influence: Increase the involvement and influence of those living with Parkinson's disease in federal and state legislation, using the Morris K. Udall Parkinson's Research Act and the appropriations process. Use the same influence to speed regulatory approval of Parkinson's treatments, ensure Medicare and private compensation for experimental therapies, and prevent employment discrimination against Parkinson's-affected workers

Network: Develop an informed and effective grassroots network—involving individuals afflicted with the disease, their families, Parkinson's foundations, support organizations and active physicians and scientists.

Parkinson's and politics

BY LEAH K. GLASHEEN

Veteran journalist Morton Kondracke sits in his Washington office, talking about his new book. He is a consummate Washingtonian—engaging, direct, immersed in many things at once.

Surrounded by headlines from Roll Call, the Capitol Hill newspaper he oversees, he compresses into less than an hour everything he wants to say. Then he's up and ready to go: back to the computer that nearly lost today's editorial; back to the myriad things that clamor for attention from a man who edits a newspaper, co-hosts a TV show and contributes regularly to a major news channel.

The only thing that derails Kondracke from his juggling is a question from a colleague: "How's Milly?"

Kondracke stops in his tracks.

"She's having a feeding tube installed. It's less of a big deal than I thought," he says, almost apologetically.

If there's a center to Kondracke's whirlwind, it's not his career. It is his wife of nearly 34 years, Milly, a former psychotherapist and mother of their two children.

In 1988, when Milly was diagnosed with Parkinson's disease, a progressive neurological disorder, Kondracke says he was "pretty naive" about the disease, the devastation it could cause and the barriers to a cure.

He chronicles the effects of Parkinson's on his wife, himself and their family in his new book, "Saving Milly: Love, Politics, and Parkinson's Disease" (PublicAffairs, 2001). He also explains why advocating for more federal spending on disease research has become "his" cause.

"In the first five years that Milly had Parkinson's, I naively thought disease funding was an objective, scientific process, sort of apart from politics."

Kondracke recalls. But when he saw that the budgetary process pitted one disease group against another, and that precious few dollars went to Parkinson's research, he decided to become active in pushing for more money.

In the early 1990s, he met super-lobbyist Terry Lierman. "The upshot of his tutorial was that research itself produces miracles for mankind, but getting the money for it is as dog eat dog as any other kind of politics."

NIH spending; the agency is on track to double its 1998 budget by 2003.

Though gratifying, that's not enough for Kondracke. He wants to see the budget double again within the next five years.

Journalist Morton Kondracke believes the cure for Parkinson's disease is more money and research. His wife Milly, below with daughter Andréa in the 1970s, has the disorder.



"Terry told Milly and me," Kondracke says, "that diseases were allocated research money based on the clout of their advocates" in the White House, Congress, the media, public opinion and the National Institutes of Health (NIH), which supports most U.S. health research.

Kondracke threw himself into fundraising and lobbying, alongside others who sought more money for Parkinson's and other diseases. Their efforts may have been why Congress increased

"We're in sight of so many breakthroughs—disease breakthroughs, genetic breakthroughs... it would be a tragedy not to continue this progress."

Initially, Kondracke pushed solely for an increase in Parkinson's funding. But, he says, he came to believe that supporting an overall increase in NIH spending was the better way to go. It's bad strategy, he says, to fight with AIDS activists or

breast cancer survivors or Alzheimer's victims over whose disease is "more deserving."

Kondracke still bristles, though, at what he sees as an underfunding of Parkinson's; he hopes continued pressure on Congress—and attention brought by actor Michael J. Fox and former Attorney General Janet Reno—will translate, ultimately, into a cure.

"Practically every American has a stake in this," he says. He hopes others will pitch in by urging members of Congress and the president to fund more health research.

It is likely that any advance will come too late for Milly. "She's struggling," he says candidly.

When Milly got sick, "my first job was convincing her... that I would stick by her," Kondracke explains.

"There was never a question that I was not going to. But I had to convince her."

Theirs has not been a placid marriage, says Kondracke. He paints a portrait of the former Millicent Martinez as a vivacious, generous woman whose difficult childhood makes abandonment an ongoing worry. He describes himself as curmudgeonly, self-absorbed and, at one time, alcoholic. But he also describes himself as a man transformed by the need to step up to the plate. After Milly's diagnosis, he says, "I became a dedicated partner." Not a saint, he stresses—just a loving husband.

In fact, getting him to stop drinking was one of the last exercises of Milly's old power, says Kondracke. Ironically, it was his new sobriety and commitment to Milly that enabled him to rise to the challenge of losing, slowly, the woman he calls his "best friend."

Personality

MORTON KONDRACKÉ

FOR A HARD-BITTEN journalist, Kondracke is positively starry-eyed about the potential of research into the human brain. "It's the last frontier, next to deep

space," he says. "We need a Manhattan Project for the brain." Why? Because curing disease will save money, he maintains, by staunching the flow of dollars now spent on treatment.

Brain research is a great bargain, concurs Robert Butler, CEO of the Interna-

tional Longevity Center in New York. "[The brain is] the most complex pace-maker for life and aging," he says, adding, "We've already had the decade of the brain, but a decade is not enough."

Ever the advocate, Kondracke presents

his vision for the future. "George Bush could be the hero... by aspiring to the legacy of healer. He could be the guy who cured cancer. He could cure Parkinson's, Alzheimer's. He could," says Kondracke, "be the guy who presides over the beginning of the end of disease."

AARP

Parkinson's Action Network: Action Is the Operative Word



Joan Samuelson, President

The Parkinson's Action Network (PAN) was created in 1991 to give voice to a community that was largely invisible and, as a consequence, lacked adequate federal research funding. PAN's mission has been to educate the country and its leaders about the need to speed research, deliver breakthroughs, and cure Parkinson's disease. Throughout this effort, the scientific community has partnered with PAN to inform the nation's leaders and members of the media about promising research that needs funding.

In its ten years of operation, PAN has fought for increases in the amount of research funded by the National Institutes of Health (NIH), worked to develop a highly regarded research program in the Department of Defense, and has opposed limitations on funding for research using fetal tissue and stem cells. Much has been accomplished:

- Reported NIH Parkinson's funding has grown from \$26 million to \$155 million, and, pursuant to a congressional mandate, NIH has developed a Parkinson's research agenda calling for \$1 billion in funding over five years.
- The overall NIH budget is on track to double by 2003.
- The Department of the Army's Neurotoxin Exposures Treatment Program (NETRP) has funded \$95 million in grants targeted at Parkinson's.
- The pro-stem cell research movement has gained considerable momentum.
- A new Department of Veterans Affairs research program for Parkinson's has been created.

These goals have been accomplished through a national volunteer "advocate army" of patients and scientists from across the country. People who can speak from the heart about the devastating impact of Parkinson's and the breakthroughs that will result from a fully funded research effort are extremely effective in educating members of Congress and their staffs about Parkinson's and the need for an increased federal commitment.

There is a lot to do in the coming months, and PAN needs the research community's help:

- Congress must ensure that the scheduled \$143 million increase in Parkinson's funding in fiscal year 2002 is funded and spent.
- Congress needs to provide the funds for the NIH doubling to continue—without taking funds from other science programs to do it.
- The stem cell fight—which all Capitol Hill observers expect to continue regardless of a presidential decision—must be won decisively on the side of funding all promising research, including adult and embryonic stem cells.

- The Army's NETRP—which researchers tout as highly effective—should be funded to the full amount of \$50 million.

PAN cannot accomplish all this alone. It is vital that the scientific community join with patient advocates to help convey the importance of greater investment in medical research. Scientists can help educate members of Congress and the administration about how essential federal research investment is to scientific endeavors.

The Coalition for the Advancement of Medical Research (CAMR) is a good example of this kind of cooperative effort. Soon after the Bush administration announced it would suspend the Clinton administration's guidelines governing the use of stem cells for research, universities, scientific societies, and patient advocates came together to form CAMR. Since then, CAMR members have worked to educate Washington about the remarkable lifesaving potential of embryonic stem cells. The many letters and phone calls from research proponents have made a sizable impact, shifting public opinion and pressure solidly in favor of research. When rumors surfaced that a stem cell research decision from the White House was

It is vital that the scientific community join with patient advocates to help convey the importance of greater investment in medical research.

imminent, CAMR members flooded the White House with more than 18,000 calls—so many that the voicemail system was overloaded. Members of Congress favoring federal funding for stem cell research now range from longtime supporters to new advocates such as Senator Orrin Hatch (R-UT), a pro-life conservative.

Please help PAN accomplish this year's funding and policy goals! Visit www.parkinsonsaction.org, e-mail info@parkinsonsaction.org, or call 1-800-850-4720 or 703-518-8877.

Researchers and Advocates: A Formidable Alliance

The Advocacy Forum column is part of SFN's mission to foster open communication and collaboration between advocacy representatives and researchers. SFN is also pleased to hold its annual Advocacy Breakfast in San Diego as part of the Annual Meeting. The event is an important forum for discussing how to work together more effectively as proponents of neuroscience research. Also, advocates will have the opportunity to learn about the latest research on the disease areas they represent through poster tours and discussions with scientists in their fields of interest. For more information on the Advocacy Program, contact Allison Wainick at allisonw@sfn.org.

UCLA MAGAZINE

Alumna profile:

Joan I. Samuelson '72

Taking action

When Joan Samuelson received her degree in public service — a social science major involving the study of public policy and ways to influence it — little did she know how useful it would be. Someday.

But in 1972, Samuelson had no way of foreseeing the life-altering bombshell that would be dropped on her 15 years later: At 37, she was diagnosed with Parkinson's disease.

Within a few years, tremors were affecting her work as an attorney, and Samuelson decided to switch professional gears. Around that time, she read about a fight in Congress over fetal-tissue transplant research. Excited about the potential benefits of such research, she contacted the office of the congressman leading the struggle, UCLA alumnus Henry Waxman '61, J.D. '64. "I asked them what I could do, thinking they'd say, 'Write a letter,'" says Samuelson. "And they said, 'Could you come and testify? We don't have anybody who knows anything about Parkinson's in Washington.'"

On Capitol Hill, Samuelson got a real education in public policy. "I realized that our invisibility in Washington was costing us hundreds of millions of dollars in research money and slowing down our cure."

And thus was born the Parkinson's Action Network, an organization dedicated to promoting support for research aimed at finding a cure. As



president, Samuelson handles lobbying efforts with Congress and the administration and works with the scientists, checking on their progress and their needs.

Samuelson's hard work and commitment have paid off. In 1997, Congress passed the Morris K. Udall Parkinson's Disease Research Act, which called for increased spending in research and the establishment of research centers, one of which is at UCLA. Two years later, Samuelson got the opportunity to plead her case before a Senate subcommittee — alongside actor Michael J. Fox, whose own revelation about having the disease greatly helped the cause.

"I knew if Michael was there, America would watch," Samuelson says. "That public recognition has made a big difference. We got a research plan approved by Congress that would fund a billion dollars over five years to get a cure for Parkinson's."

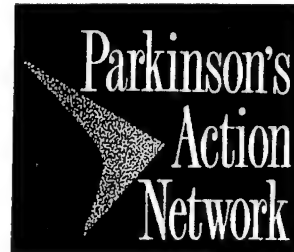
As she enthuses about the medical findings that will hopefully bring about that cure — cell transplantation, nerve-growth factor, brain repair — it's clear the former lawyer is getting a new education. "I didn't take one science course at UCLA and I was happy not to," Samuelson admits. "Now I have to catch up."

— Sandy Siegel '72

Joan I. Samuelson

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Education

Boalt Hall School of Law, University of California at Berkeley

Juris Doctor awarded 1977. Member, California Law Review. Publication: *Employment Rights of Women in the Toxic Workplace*, 65 Cal. L. Rev. 1113 (1977). Admitted to the California Bar 1977.

University of California at Los Angeles

Bachelor of Arts awarded cum laude 1972. Major: Public Service

Current Occupation

Founder and President, Parkinson's Action Network, 1991 to the present.

Legal Employment

- 1985-1991 Lawyer in private practice (Civil dispute resolution, state and federal court litigation and mediation representing clients including municipalities, businesses and private individuals); *Of Counsel*, Walter & Pistole, Santa Rosa, California; *Of Counsel*, Law Offices of Alan B. Pick, Los Angeles, California.
- 1982-1985 Member, trial and appellate team prosecuting *Van de Kamp v. Bank of America* (class action challenging trust account cash management), Los Angeles, California; Consumers Union of U.S., Inc. (legislative analysis and advocacy, lawyer training), San Francisco, California; other civil litigation and mediation (*Munger, Tolles & Olson*, Los Angeles, California; *Lobdell, Miller, Samuelson & Sher*, Palo Alto, California).
- 1977-1982 Petty, Andrews, Tufts & Jackson, San Francisco, California (general commercial litigation and arbitration, state and federal courts).

Other Employment

- 1982-1984 Executive Director, Berkeley Law Foundation, Berkeley, California. Part-time director of operations for non-profit legal foundation providing financial support for public interest legal work. Supervised fundraising, public relations, finances, grant-making, grantee operations; directed development and planning.
- 1975-1976 Permit analyst, writer and legal researcher, California Coastal Zone Conservation Commission.
- 1971-1974 Special Assistant and Local Issue Coordinator, United States Senator John V. Tunney, San Diego, Los Angeles and San Francisco. Conducted issue analysis and legislative development, supervised constituent relations, organized special events.

Awards

- Research!America Award for Exceptional Contributions as a Volunteer Advocate for Medical Research, March 2001.
- American Society for Neural Transplantation award for "outstanding efforts and support for research in Parkinson's disease," February 1997.
- Boalt Hall School of Law Alumni Association's 1996 Distinguished Service Award.
- Named one of the year's "Legal Eagles" by *California Lawyer* magazine in 1996.
- California Business and Professional Women, 1993 Hall of Fame Award in Government.

Speaking, Lecturing and Media – Parkinson's-related

Testimony to committees of the United States House of Representatives (2001, 1999, 1998, 1997, 1993, 1992, 1991) and United States Senate (2001, 1999, 1996, 1995, 1992); speeches and presentations to Parkinson's groups nationwide, 1990-present; guest of radio and television panels and interviews including NBC Today Show, NBC, ABC and CBS News, CNN, C-SPAN, MSNBC, Fox News, 20/20, Dateline NBC, Montel Williams, Jane Whitney, and Jack Anderson, 1990-present. Seminar presenter, numerous panels including 2001 Society for Neuroscience Panel on Animal Rights, November 2001; Symposium on Science and Public Policy, Beckman Center for Molecular and Genetic Medicine, Stanford University Medical Center, 1992.

Speaking and Lecturing – Other

Moderator, Consumers Union training seminar on housing discrimination, June 1986; panelist, Practicing Law Institute on Occupational Health, 1978 and 1981; panelist, California Medical Association's Annual Scientific Assembly, *The High Risk Worker*, 1981; speaking and panelist to other legal, medical, industry and consumer groups.

Organizational and Civic Involvement

Current: Board of Directors, The Parkinson's Institute, Sunnyvale, California; Executive Committee member, Funding First, Washington, D.C.

Former: Board of Directors, Berkeley Law Foundation; Member, City and County of San Francisco Citizens Committee on Community Development; pro bono legal work for San Francisco Lawyers' Committee for Urban Affairs and Public Advocates, Inc., San Francisco, California; assistance to local and statewide electoral campaigns.

Elisabeth Bresee Brittin
Executive Director, Parkinson's Action Network

Elisabeth Bresee Brittin joined the Parkinson's Action Network (PAN) in March 2001 to lead the new national headquarters in the Washington Capital Area. PAN is the leading advocacy organization promoting an increased public research investment in Parkinson's disease with a goal of finding a cure by the earliest possible date. PAN is a non-profit organization established in 1991.

Ms. Brittin has extensive experience in the federal government, having been a public servant for the past eleven years. Until January 2001, Ms. Brittin was the Assistant Secretary (Enforcement) at the U.S. Department of the Treasury, a position to which she was appointed by the President and confirmed by the U.S. Senate. Ms. Brittin was at Treasury since 1994, where she also served as Deputy Assistant Secretary (Law Enforcement) and Director of the White House Security Review. In those positions, Ms. Brittin gained tremendous experience working with the U.S. Congress and the Executive Branch, and in particular worked on appropriations issues, including testifying at Congressional hearings. Prior to leaving the Department, the Secretary awarded her *The Treasury Medal* for exceptional service.

Before joining Treasury, Ms. Brittin served as an Assistant United States Attorney for the District of Columbia where she prosecuted criminal cases. She began her career as an attorney in private practice with the law firm of Williams & Connolly in Washington, DC. Ms. Brittin has a law degree from Georgetown University Law Center (*cum laude*) and a bachelor's degree from Ithaca College (*magna cum laude*).

Over one million people suffer from Parkinson's disease. This is a very promising time in the field of medical research for Parkinson's. With proper focus and funding, scientists believe that a cure is possible within the next five years. PAN is on the front lines of the effort to secure additional research funding, as well as to ensure that public policy supports the Parkinson's agenda.

Ms. Brittin has had personal experience with this devastating disease. Her father was diagnosed with Parkinson's disease at the age of 39, shortly before she was born. In addition, her maternal grandmother and her uncle, her mother's brother, had the disease. Ms. Brittin was born and raised in Oneonta, New York.

In her short time with PAN, Ms. Brittin has become an outspoken advocate in support of federal funding for embryonic stem cell research. She has participated in numerous live debates on national television, including CNN's Talk Back Live, MSNBC, CNBC and Fox News. She also serves on the Board of Directors as Treasurer of the Coalition for the Advancement of Medical Research (CAMR).

John C. Rogers

Education and Advocacy Director

John C. Rogers began his work with PAN as a volunteer. Having built the successful government relations firm of PACE-Capstone, John decided to focus his talents on a disease that had inflicted real pain on his family.

John started his relationship with PAN in January of 2000 as a volunteer and was named the Education and Advocacy Director in March 2001. He has worked in and around government for almost 20 years. John has substantial experience working with the Congress, the Administration, other agencies, as well as state and local governments. .

On behalf of PAN, John is a founding member and currently serves on the Board of the Coalition for the Advancement of Medical Research (CAMR), a coalition of patient advocacy groups and academic institutions that are leading the fight for the continuation of regenerative medicine research such as stem-cell and therapeutic cloning - SCNT.

In addition to his work with PAN, John is currently a partner with the government relations firm, PACE-Capstone. While we at PAN occupy the majority of his time, he also represents decision makers for businesses, communities, associations and non-profits in their work with and before the government.

Prior to co-founding PACE-Capstone, President Clinton appointed John to the post of Deputy Assistant Secretary of Plans and Operations and Principal Deputy Assistant Secretary of Defense for Legislative Affairs at the Department of Defense. Before serving at the Department of Defense, John was Congressman Les Aspin's District Director and National Political Director. John also had a tour of state government, serving as the Senate Caucus Director in Wisconsin. Rogers was born and raised in Chicago and completed his schooling at the University of Iowa. Mr. Rogers was also an Adjunct Fellow at the Center of Strategic and International Studies.

John has a personal commitment to Parkinson's, which is why he became involved with PAN – he watched his grandmother and his father suffer with the disease. He decided to channel his anger against PD and has been fighting for a cure ever since. His advocacy experience working with Congress and the White House are already proving invaluable to PAN's mission.

Laura Lytle Eckart, Deputy Education and Advocacy Director

Laura comes to the Parkinson's Action Network after five years at the United States Senate Press Gallery, a government office that facilitates coverage of the United States Senate for national and international newspapers. In her role at the Press Gallery, Laura worked closely with staff members of all political affiliations and offices. She is a graduate of Virginia Tech (B.A. Communications, 1996). Having family ties to Parkinson's, Laura is happy to be an advocate for this great cause, using her experiences from working on Capitol Hill to benefit the Parkinson's community.

Michael Everts, Financial Officer

Michael joins the staff of the Parkinson's Action Network after serving as the Director of Finance and Administration of the Liberty Education Forum & Log Cabin Republicans. In his position at LEF & LCR, Michael was responsible for financial management, Congressional lobbying, development, grassroots organizing, and communications duties. In that position, he learned a great deal about how non-profit organizations operate. He is a graduate of the Lock Haven University of Pennsylvania (B.A. Political Science, 1998). Michael is pleased to have joined the Parkinson's Action Network, putting his experiences to work for an excellent cause.

Jeannette Maurer, Administrative Assistant

Jeannette is a 2001 graduate of Loyola College in Maryland (B.A. Political Science, 2001). Jeannette is excited to join the Parkinson's Action Network and work for such an important cause. Prior to joining PAN, Jeannette has worked for two newspapers, including the Baltimore Sun. Jeannette has personal ties to Parkinson's, as her grandmother presently suffers from the disease.

Christy Hahn, Executive Assistant

Christy is a 2000 graduate of Louisiana State University where she received a BA in Political Science. She participated in several political campaigns and served as Vice-President of the College Republican Alliance of LSU. Since moving to the DC area, Christy has completed an internship with the Congressional Management Foundation and worked in Government Affairs for Northeast Utilities System. Christy is responsible for planning PAN's Eighth Annual Public Policy Forum scheduled for May 2002.

Erik L. Oksala, Executive Assistant

Erik is a recent graduate of Goucher College in Baltimore, Maryland, where he received a BA in Political Science (1999), with a concentration in Public Policy. Prior to joining PACE-Capstone and PAN, Erik was a program coordinator for the National Park Trust. He has also worked on numerous political campaigns.



Parkinson's Action Network

Grassroots Advocacy Program

The Parkinson's Action Network (PAN) is committed to establishing a national grassroots advocacy program. PAN can only accomplish its mission with strong grassroots support. PAN and the Parkinson's community at large are best able to reach the goal by blending a strong grassroots effort with a professional staff that has significant government experience. Thanks to prior advocacy efforts, PAN has been successful in increasing awareness about Parkinson's and increasing federal funding for Parkinson's research. However, the job is far from finished.

PAN is dedicated to finding a cure for Parkinson's disease as soon as humanly possible, but we cannot do it alone. We know that a cohesive, effective and motivated grassroots community is vital to make PAN's mission a reality. We need your help. Become an advocate and volunteer your time and energy to this important cause. Together we can make a difference.

In order to create the most cohesive program possible, PAN is creating a two-tiered plan: PAN will appoint dedicated activists with a specific set of skills to serve in two positions: State Advocacy Coordinators and Congressional Advocacy Coordinators. State Advocacy Coordinators will serve as PAN's primary contact and will be responsible for coordinating Parkinson's advocacy efforts statewide. Congressional Advocacy Coordinators will be responsible for coordinating Parkinson's advocacy efforts within their Congressional district and will be responsible for working and communicating directly with State Advocacy Coordinators. PAN will give priority attention to recruiting volunteers in states and districts represented by key appropriators.

PAN will serve as the information center of the grassroots efforts with advocates providing local support by conducting outreach to their member of Congress and to the Parkinson's community. PAN's responsibilities in grassroots advocacy include:

- Hosting conference calls on a regular basis to keep advocates apprised of issues.
- Coordinating yearly Public Policy Forum.
- Educating the Parkinson's community by providing Action Alerts and Washington Updates via electronic mail.
- Attending scientific conferences to keep abreast of the latest research.
- Coordinating grassroots efforts nationwide.
- Providing educational materials including, but not limited to: Advocacy Handbooks, sample letters, and fact sheets.
- Maintaining comprehensive, educational and interactive website.
- Providing Action Reporter newsletters.
- Implementing public policy strategies.

Role of State Advocacy Coordinator

PAN is recruiting and appointing members of the Parkinson's community to serve as volunteer State Advocacy Coordinators for their individual state. The primary role of a State Advocacy Coordinator is to facilitate grassroots efforts statewide. Candidates for this position must have substantial knowledge of the Parkinson's advocacy movement. This position requires a dedicated advocate who has the time, energy and resources to devote to this effort.

State Advocacy Coordinators will act as the primary contact for PAN and for Congressional Advocacy Liaisons. State Advocacy Coordinators will spread PAN's message to the public, Members of Congress, the White House and to the Parkinson's community. This position requires two distinct skill sets: both technological and interpersonal communications skills are required. PAN recognizes that many talented candidates may not have both of the skill sets and therefore it may be necessary to have more than one person in this position for any given state. This position requires a great deal of work, but also offers many rewards.

Responsibilities of a State Advocacy Coordinator include:

- Serving as primary contact with PAN for any given state.
- Serving as primary contact for Congressional Advocacy Coordinators.
- Filtering and disseminating information to PAN from the field.
- Interacting with Members of Congress, local media and other policy and scientific leaders.
- Educating the public, Congress, the media, local support groups, medical offices about the Parkinson's Action Network and Parkinson's disease.
- Developing and implementing a communication strategy statewide. This will include building an extensive **electronic mail address book** and building a **phone tree** for those who do not have electronic mail.
- Maintaining contact with scientists in their states.
- Representing the Parkinson's community with Members of Congress from their individual state.
- Coordinating PAN's grassroots campaign statewide.
- Informing and empowering state Parkinson's support groups and members of the community of PAN's actions.
- Spearheading statewide grassroots efforts, i.e. letter writing campaigns, local fundraisers, etc.
- Educating local Parkinson's community and initiating action within that community.
- Attending PAN's yearly Morris K. Udall Awards Dinner to the extent possible.
- Attending PAN's Public Policy Forum to the extent possible.
- Encouraging other advocates from the state to attend Morris K. Udall Dinner and the Public Policy Forum and encouraging others to sponsor these events.

Role of Congressional Advocacy Coordinator

PAN is also recruiting and appointing members of the Parkinson's community to serve as Congressional Advocacy Coordinators. The Congressional Advocacy Liaison will be appointed to serve in the Congressional district where he or she resides. The primary role of a Congressional Advocacy Coordinator is to spread PAN's message to the public, Members of Congress, the White House and to their local Parkinson's community. Candidates for this position must stay abreast of national Parkinson's related public policy issues and inform and motivate their local Parkinson's grassroots community. Responsibilities of a Congressional Advocacy Coordinator include:

- Reporting directly to the State Advocacy Coordinator on events and actions in their Congressional district.
- Coordinating PAN's grassroots campaign within their Congressional district with other Parkinson's advocates in their area.
- Serving as Primary Point of Contact for advocates in their district.
- Educating local Parkinson's support groups and members of the community of PAN's actions.
- Spearheading local grassroots efforts, i.e. letter writing campaigns, local fundraisers, etc.
- Implementing a local communication structure, which disseminates information to local Parkinson's community.
- Motivating local Parkinson's community and instigating action within that community.
- Representing the Parkinson's community with the Member of Congress from their district.
- Attending PAN Public Policy Forum and the Morris K. Udall Awards dinner to the extent possible.
- Encouraging other advocates from the state to attend Morris K. Udall Dinner and the Public Policy Forum and encouraging others to sponsor these events.

We hope that you will join in our efforts. If you are interested in becoming a State Advocacy Coordinator or a Congressional Coordinator, please let us know by reaching us at the contact information below.

E-mail: info@parkinsonsaction.org

Website: www.parkinsonsaction.org

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**BACKGROUND PAPER
SOMATIC CELL NUCLEAR TRANSFER
(aka "Therapeutic Cloning")**

OVERVIEW:

Regenerative medical research has the potential to lead to new therapies or cures for many currently incurable disorders including Parkinson's, Alzheimer's, spinal cord injuries, heart disease, ALS, various cancers, among others. One form of this research is somatic cell nuclear transfer (SCNT), which is commonly known as "therapeutic cloning". With SCNT, scientists may be able to grow new cells to replace those damaged or lost by Parkinson's and other disorders, thus restoring lost function, improving the quality of life and perhaps even curing the disease.

However, one of the more troubling things occurring in Washington today is the attempt by some politicians to ban and criminalize this exciting new avenue of scientific research. We agree that human reproductive cloning should be outlawed and support legislation that would do that. However, there is a bill pending in the Senate that would outlaw SCNT as well. This bill, S. 1899, was introduced by Senators Brownback (R-KS) and Landrieu (D-LA).

SCNT (aka "Therapeutic Cloning") is about saving and improving lives. It is fundamentally different from human reproductive cloning; SCNT produces stem cells, not babies.

- In SCNT, the nucleus of a donor's unfertilized egg is removed and replaced with the nucleus of a patient's own cells, like a skin, heart, or nerve cell. These types of cells are called somatic cells.
- The goal of SCNT is to develop stem cells that will not be rejected or destroyed by the patient's immune system.
- NO sperm is used in this procedure.
- The cells are not transplanted into a womb.
- The unfertilized egg cells are stored in a petri dish to become a source of stem cells that can be used to treat life-threatening medical conditions.
- SCNT aims to treat or cure patients by creating tailor-made, genetically identical cells that their bodies won't reject. In other words, SCNT could allow patients to be cured using their own DNA.

We adamantly oppose reproductive cloning, which aims to create human beings by cloning human embryos.

LEGISLATION:

S. 1899, introduced by Senators Brownback (R-KS) and Landrieu (D-LA), would ban and criminalize SCNT. If approved, this bill would have devastating results and cut-off hope to millions of Americans with life-threatening diseases. It would also:

- Make it illegal for U.S. citizens to seek SCNT treatment abroad. This means that a patient who may have little hope left could be thrown in jail upon re-entry to the U.S. if they went to another country to have treatment using SCNT.
- Send a U.S. scientist to jail for developing SCNT therapies in a petri dish.
- Make it illegal for U.S. scientists to import SCNT therapies that were developed in other countries.
- Passage of the Brownback-Landrieu bill -- or any ban on this research -- runs counter to our nation's history as the world's leader in biomedical research.
- Even a temporary ban on SCNT (such as a moratorium) would cripple this promising field and delay patients' access to potentially life-saving treatments.

In contrast, S. 2439, sponsored by Senators Specter, Feinstein, Hatch and Kennedy, would ensure that this critical medical research is allowed to continue. This bill would:

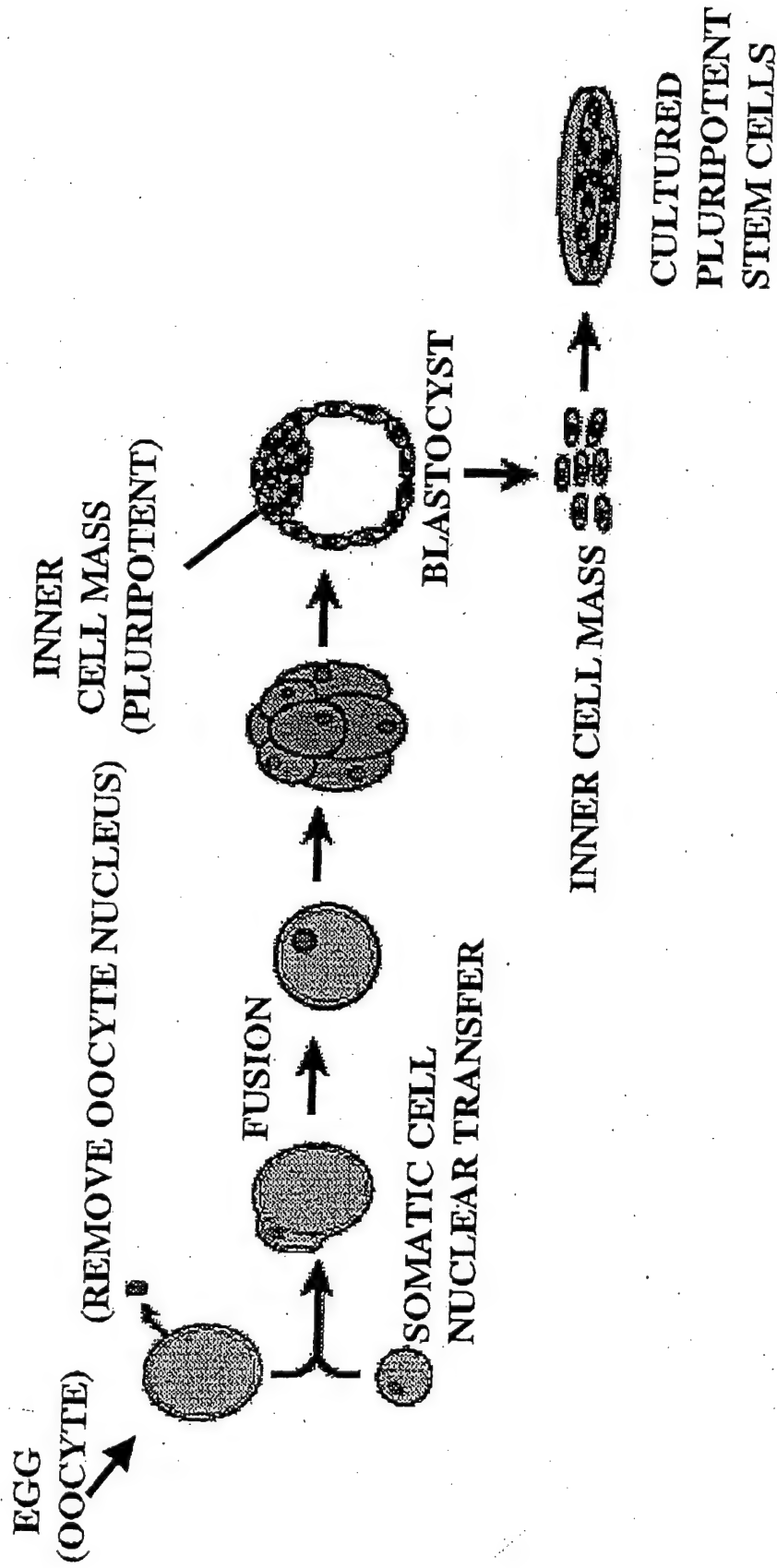
- Establish rigorous oversight of the research, including review by an ethics board.
- Explicitly ban human reproductive cloning and impose severe penalties -- including jail time and million-dollar fines -- on scientists who pursue human cloning.

THE ASK

Specifically, we ask that you:

- **Vote AGAINST S. 1899** when it reaches the Senate floor for a vote.
- **Vote FOR S. 2439** when it reaches the Senate floor for a vote.
- Support federal funding for all potentially life-saving regenerative medical technologies, including stem cell research.

WHAT IS NUCLEAR TRANSPLANT TECHNOLOGY?





TALKING POINTS ON SOMATIC CELL NUCLEAR TRANSFER (aka "Therapeutic Cloning")

- Somatic Cell Nuclear Transfer (commonly known as "Therapeutic Cloning") is about saving and improving lives.
- It is fundamentally different from human reproductive cloning; SCNT produces stem cells, not babies.
- The goal of SCNT is to develop stem cells that will not be rejected or destroyed by the patient's immune system.
- SCNT could lead to dramatic new treatments and cures for now-incurable diseases and medical conditions such as Parkinson's, cancer, Alzheimer's, diabetes, spinal cord injuries, heart disease, ALS, and other devastating conditions.
- Patient advocacy groups, leading scientists -- including the National Academy of Sciences -- and a huge majority of the American people agree that human reproductive cloning should **not** be pursued.
- S. 1899, introduced by Senators Brownback and Landrieu, cuts-off hope to millions of Americans with life-threatening diseases by banning SCNT.
- The bill could send scientists and patients to jail for pursuing this research.
- Passage of S. 1899 -- or any ban on this research -- runs counter to our nation's history as the world's leader in biomedical research.
- We urge you to **vote AGAINST the Brownback Bill** when it reaches the Senate floor.
- In contrast, S. 2439, sponsored by Senators Specter, Feinstein, Hatch and Kennedy, would ensure that this critical medical research is allowed to continue.
- This bill establishes rigorous oversight of the research, including review by an ethics board.
- It also explicitly bans human reproductive cloning and imposes severe penalties -- including jail time and million-dollar fines -- on scientists who pursue human cloning.
- We urge you to **vote FOR Specter/ Feinstein/ Hatch/ Kennedy Bill** when it reaches the Senate floor.

Morton Kondracke

Morton Kondracke, a 37-year veteran journalist, joined the FOX team in October 1996 and became co-host of *The Beltway Boys*, along with Fred Barnes, executive editor of *The Weekly Standard*. Kondracke is also a regular contributor on Fox News Channel's *Special Report with Brit Hume*, the #1 weeknight political program on cable.

He served 16 years as a regular panelist on the NBC/PBS public affairs show, *The McLaughlin Group*, seen on over 350 stations nationwide.

Before becoming the executive editor and columnist of *Roll Call*, the Hill's feisty independent newspaper, Kondracke served as executive editor and senior editor of *The New Republic* from 1977-1991. He was Washington bureau chief of *Newsweek* and was a regular panelist on "This Week with David Brinkley," and a columnist for *The Wall Street Journal*. In addition, Kondracke received the *Washington Post* "Crystal Ball Award" in 1994 for predicting the Republican takeover of Congress and was runner-up in 1996.

Kondracke chronicled his wife Milly's struggle with Parkinson's disease in his 2001 book entitled *Saving Milly*. Personally and professionally dedicated to finding a cure for Parkinson's disease, he is a member of both the Parkinson's Action Network and the Michael J. Fox Foundation for Parkinson's Research.

Kondracke graduated from Dartmouth College and was a Nieman Fellow at Harvard University

The Reviews Are In!

“Saving Milly”

by Mort Kondracke

Intelligent, illuminating, insightful, sitting there at my dining room table Mort Kondracke was also, in a word, passionate — Michael J. Fox, Foreword, “Saving Milly”

... moving and impossible to put down. . . Four stars. —Larry King, “USA Today”

... one of those uncommon books that manages—quietly, beyond any expectations—to ennoble its author and its readers alike.... ‘Everyone becomes a better person because of Milly,’ a friend once told Mr. Kondracke himself—and it may be true, too, of any reader lucky enough to come upon this beautiful book. —Wall Street Journal

[Kondracke’s] unvarnished, highly detailed account of the burdens of loving care is unforgettable. —The New Republic

Morton’s love for Milly has been unfailingly strong and steadfast...in sickness and in health. —Katie Couric co-anchor, NBC News’ TODAY

... extraordinarily moving . . . —Christopher Reeve, author of “Still Me”

Thursday, May 31, 2001



By Emille Sommer, USA TODAY

"Milly transformed my life": So says journalist Morton Kondracke, who has written *Saving Milly: Love, Politics, and Parkinson's Disease*, as a love story to his wife of 33 years, Milly, who has Parkinson's disease.

TV journalist & wife wage war on Parkinson's

Mort Kondracke tests the rules of his craft as he works to secure money to battle the debilitating disease

By Susan Page
USA TODAY

WASHINGTON — These days only Morton Kondracke can understand the faint speech of his frail wife, leaning in nose-to-nose to listen as she struggles to discuss the Parkinson's disease that has muted her voice and soon might take her life.

How would she describe their 33-year marriage?

"Exciting," Milly Kondracke whispers, her husband repeating the answer aloud. "Passionate," she says, all but inaudible. He laughs with delight. "Friends."

**Cover
story**

For most of their time as a couple, Mort Kondracke has been the one in the spotlight: as a newspaper columnist, Washington bureau chief, magazine editor and TV pundit — one of the original panelists on the bombastic syndicated *McLaughlin Group* and now co-host of Fox TV's *Beltway Boys*.

He covered politics and questioned presidents; she worked as a psychotherapist and bore the brunt of rearing their two daughters, now grown, as he focused on his career.

But their lives have been transformed and their roles in some

Please see COVER STORY next page ►

around his wife's stooped shoulders in the apartment that she no longer could tolerate their house in the city. When their daughters are in adolescence, Milly organizes the neighborhood's parents' information-sharing network to help them manage their children's behavior. She battled the school district to get special help for her son who has dyslexia. She pushed her husband's bottles of gin and tonics down the drain and convinced him to stop drinking; he finally joined Alcoholics Anonymous.

All that has made the Milly faces at age 61 is striking to her friends and family.

Some people with Parkinson's successfully control the tremors for years, and Milly was helped by the drug levodopa. But it gradually lost its effectiveness, and two experimental surgeries failed to improve her condition. The Kondrackes pursued alternative treatments, consulted a herbal therapist in Chicago and a woman in New York who massaged victims of the disease.

Now Milly's body is in the wheelchair she must use. She has trouble swallowing; her food must be cut up in tiny pieces and mashed before she can eat it.

Since his wife became ill, Mort Kondracke says his Chris-

Fighting for lives

Continued from 1A

ways reversed since the moment when she remarked in 1987 that she was having trouble writing the letter "K" on a check for their daughter Andrea's college application.

Since then — after the process of getting the diagnosis of Parkinson's and then accepting it — Mort and Milly Kondracke have become soldiers in the political disease war. The battle for attention and funding at times pitches one disease against another, prompting arguments

Cover story

about who is worthier and calculations of the wide disparities in how many federal research dollars are allocated per patient.

As it turns out, the politics of fighting disease requires the same sort of coalition building and lobbying that marks, say, the politics of building highways. And having a celebrity who personifies the cause can make all the difference.

Which means the announcement in late 1998 by actor Michael J. Fox that he had been diagnosed with Parkinson's was tragic news for him but a ray of hope for those pushing for a cure. The degenerative neurological disorder affects about 1 million Americans in middle age or older. It causes uncontrollable tremors and muscular rigidity. The symptoms can be treated for some by drugs or surgery, but there is no cure.

"Muhammad Ali has Parkinson's, and he's done a lot, but he can't speak," Mort Kondracke says. Other big names with the ailment, Pope John Paul II and Clinton administration attorney general Janet Reno among them, weren't active in the campaign for more funding. "Parkinson's lacked for celebrity," Kondracke says. "I knew the minute Michael J. Fox announced that he had Parkinson's: Aha, this is it."

Becoming an activist

Fox's boyish good looks and earnest manner made him an engaging character in the *Back to the Future* movies and the TV series *Spin City* and *Family Ties*. Before the annual dinner of the Parkinson's Action Network last week, he seemed much like the roles he's played, greeting Milly warmly and congratulating Mort on his book, *Saving Milly: Love, Politics, and Parkinson's Disease*, being published Friday.

"You're not the only one who can write a book," teased Fox, whose



Exhausting the remedies: Milly Kondracke has tried a variety of therapies in her fight against Parkinson's.

own book is to be published in January. "College. Journalist," he pointed to Kondracke. "But," he said, pointing to himself and smiling. "His wife, actress Tracy, joined in the laughter."

Later, at the dinner, Fox, ABC correspondent Sam Donaldson, the master of ceremony, mistakenly showing up in black tuxedo. "The other men are in business," he said, pointing to himself and smiling. "Sam, sorry about that," Fox said from the dais, explaining to the crowd, "I saw him earlier and asked him for a drink" on the assumption that he was a waiter.

But the toll that Parkinson's has taken on Fox's body, if not his humor, was unmistakable. He jammed his hands in his pockets, but tremors shook his left arm and right leg rocked to its own rhythm.

Fox is a hero to many in the Parkinson's community because he has adopted the cause as his own, testifying before Congress and starting the Michael J. Fox Foundation for Parkinson's Research.

For Kondracke, the decision to become an activist caused considerable angst. Friends say he agonized over what a journalist appropriately could do on behalf of the cause, however laudable.

Eventually, he began to push for more funding for medical research in his column in the *Capitol Hill* newspaper *Roll Call*. He sat at meetings with members of Congress for Milly and Joan Samuelson, founder of the Parkinson's Action Network. He carried a list of names to the National Institutes of Health at the time was spending an average of \$1,000 a year on research for each person with AIDS, \$260 for each cancer patient and \$54 for each person with

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A Cure for Milly

When his wife was diagnosed with Parkinson's, he sought more funding for research in a race against time. But Washington politics made that crusade more difficult than he ever imagined

By Morton Kondracke

"MARRY MILLY!" Joan Kehoe whispered in my ear. Then she repeated it, more insistently. We were at an Italian restaurant, Riccardo's, the favorite martini-lunch spot for reporters at the Chicago Sun-Times in the 1960s. Joan had introduced me to Millicent Martinez a few months before. Milly was sitting out of earshot as Joan importuned me. She also couldn't see the quizzical look on my face, which betrayed what was in my mind: Marry Milly? Out of the question.

Not that I didn't like her. I did. She was pretty. She was self-assured. And she was exotic, half-Mexican and half-Jewish. But she did not fit my life's plan, which was to become a big-shot Washington journalist. I figured that the person I planned to be someday should have a Vassar or Wellesley graduate for a wife, or possibly an heiress—a woman whose family connections and intellectually stimulating company could help me attain the goal.

Eventually Milly overwhelmed this stupid idea and I realized that, wherever I went in life, I would regret it the whole way if she were not with me. So ultimately I followed Joan's advice.

We got married on October 7, 1967. We wrote our own wedding ceremony, praying for peace in the world and justice in America and also pledging in the traditional way that we would be there for each other in sickness and in health. Two photographers from the Sun-Times took different wedding pictures of us at separate moments leaving the church and walking to our reception.

Both show Milly and me laughing, in a state of pure joy. I felt utterly confident that I had made the best decision of my life. I have never for a moment regretted it, in health or in sickness.

In fact, for 33 years we've lived a love story—but of one kind for the first 20 and a very different kind for the last 13, after Parkinson's disease invaded our lives. We moved to Washington in 1968, and Milly developed into a dynamo—a gifted psychotherapist, a strong mother to our two daughters, a wise neighbor and generous friend, and a formidable companion to me. We were bonded, almost welded.

IN 1987, the first shadow of Parkinson's disease cast itself upon our lives. Milly was writing a check and remarked that she could not form the letter "K" correctly. She got a piece of paper and wrote her signature four or five more times, then more times, and said her handwriting just wasn't right. I saw no difference. Anyway, I thought Milly was both vain and perfectionist about her clear penmanship. Whatever was wrong—if anything was wrong—was in her imagination or was being exaggerated, I figured.

That May, Milly made an appointment to see her old boss at the Neurology Center in Bethesda, Marvin Korengold. In fact, after getting her master's degree in social work at Catholic University, Milly had counseled patients at the center for a few years. She'd brought home harrowing stories about people stricken with



Alzheimer's disease, epilepsy and particularly Parkinson's. Korengold, a neurologist, examined Milly and diagnosed ulnar neuropathy, a nerve inflamed from pressure at the elbow. He told her to try to keep her arms straight and avoid leaning on the elbow. Milly reported these findings to me with relief that the problem was not serious. But, even though she followed instructions, her symptoms did not go away.

On a follow-up visit in June, Korengold had her swing her arms and noticed that the right did not move as smoothly as the left. He prescribed Symmetrel, which Milly took believing it was meant to help her nerve problem. He did not tell her what it was actually for, evidently not wanting to scare her. She went back to see Korengold a few times during the summer because her right little finger remained weak and she began to notice a slight tremor in her right foot

MILLCENT MARTINEZ AND MORTON KONDRACK
WERE MARRIED ON OCTOBER 7, 1967, IN CHICAGO.
OPPOSITE: MILLY, FLANKED BY THE COUPLE'S TWO DAUGHTERS,
ALEXANDRA AND ANDREA, IN 1984.

when she pressed the accelerator or brake while driving.

One day in September she called me at work in tears, with a panic in her voice that I'd never heard before.

"Something terrible has happened," she said. "You've got to come home." I had a fleeting terror that one of the girls had been injured or killed. She said, "I looked up the medicine Korengold gave me in my pill book. Symmetrel is for Parkinson's disease!" I was relieved that this was not the worst possible news, but for Milly it was. "I know what Parkinson's is. I've seen people with it," she cried. "It's a horrible disease, People shake. They can't walk. They choke on their food. It can't be that!"

I drove home as soon as I could and found Milly utterly distraught. This was the first time in our lives together that I had ever seen Milly out of control. She said that if she did have Parkinson's it meant that she would have to give up her psychotherapy practice because clients would not want to be treated by someone "so pathetic." She predicted, "You won't keep loving me. You'll leave me. You don't know what Parkinson's does to people. You'll have to take me to the bathroom. You'll have to feed me. You won't want to do that."

I said rather automatically that I didn't care what happened, I'd never leave her. I meant this, too, although she was correct: I knew nothing about Parkinson's or the extreme disabilities it could cause. And, of course, her problems then were so mild that her grim predictions seemed speculative and extreme.

FOR FIVE YEARS, as is usual with Parkinson's patients, a medicine called Sinemet worked to keep her tremor and stiffness under control. But gradually, as is usual, it stopped working. She began to experience severe leg cramps. She sometimes froze in a chair, unable to move. Worst of all, she began to lose her sense of balance. She fell often, and we became regular visitors to the emergency room at Suburban Hospital, where she received stitches in her lips, forehead and chin.

Morton Kondracke is the executive editor of Roll Call, a commentator on the Fox News Channel and co-host of Fox's weekly political show "The Beltway Boys."



In 1994, as Milly's condition continued to worsen, we began looking at drastic surgical therapies to relieve the symptoms. Basically, two were available—a fetal cell transplant and a pallidotomy. I read a lot about both. Milly and I met up with Joan Samuelson, president of the Parkinson's Action Network, who got us involved in advocacy and lobbying for increased federal funding of Parkinson's research. Samuelson, a Parkinson's patient herself, put us in touch with some of the top neurologists in the country, whom I called for advice about what we should do next for Milly.

They told me that, theoretically, a fetal transplant would be the most advisable thing for a direct hit at Milly's Parkinson's. The procedure, made controversial by opposition from the anti-abortion movement, involves injecting dopamine-producing cells from aborted fetuses into the brain of a Parkinson's victim to replace those that have died. At the time we were considering the operation, federally sponsored research trials were just beginning because President Clinton, as one of his first acts, had lifted a ban imposed by the Reagan and Bush administrations.

A few doctors were performing the operation without federal sponsorship, notably a surgeon in California who was reporting dramatic results. But the researchers I talked to warned me away from him, saying that he was not publishing any scholarly findings and stories were circulating about botched operations and



One day Milly called me at work in tears, with a panic in her voice that I'd never heard before. 'Something terrible has happened,' she said.

brain damage. The experts I consulted also said that their review of results from Europe and elsewhere indicated that while fetal transplantation was a promising area of research, there were significant problems keeping cells alive after they were transferred. They advised looking seriously into pallidotomy instead. A doctor named Mahlon DeLong had been studying this daylong surgical procedure in which the patient is awake throughout, helping to guide doctors to the targets they would be trying to hit deep in the brain to slow the misfiring of hyperactive nerve cells. DeLong had been Milly's neurologist at Johns Hopkins University in Baltimore before moving to Emory University in Atlanta. He warned there was potential danger to a pallidotomy, but Milly begged him to perform the surgery. "I can't stand to live this way anymore," she said. "I'd rather die." He agreed to do it.

The first indications were good. When Milly was able to get out of bed after the surgery, she and I danced briefly around the room. Her balance wasn't perfect, but it seemed improved, and I thought she moved less haltingly than before the surgery. But the old pat-

tern resumed: Some days, she could walk around the house safely by herself or using a walker. Other times, at home and away, she collapsed forward or to the side and was unable to break her fall. The emergency room visits recurred, and the stitches. One day when our daughter Andrea was home from medical school, Milly had almost reached the bottom of the stairs when she suddenly fell forward, hitting her head on a wall. We put our three-story house on the market and signed a contract on a one-story rambler.

There was no longer much hope that Milly could avoid being rendered a permanent invalid by Parkinson's.

INSIDE AND OUT, the White House fairly shimmers with light at Christmastime. And so it did on December 15, 1993, when Milly and I made our first foray into politics as a way of saving her from Parkinson's disease.

By the time Bill and Hillary Clinton's Christmas invitation arrived, I was beginning to understand disease politics. My eyes were first opened earlier in 1993 by literature that Jill Schuker, Milly's

best friend, sent to us from the Parkinson's Action Network. It pointed out that Parkinson's research was deeply underfunded by the federal government in comparison with other diseases. The minute I read it, I felt that I'd let Milly down by not taking action earlier. I knew I had to do something, but I didn't know what. I had a twice-weekly column in *Roll Call*, a newspaper read by practically everyone on Capitol Hill, but at first it struck me that using my position to campaign for more Parkinson's money constituted unethical special pleading.

But in July of that year I decided I could write something if I disclosed my personal interest. I phoned Joan Samuelson, whom I hadn't yet met. On the basis of the interview, I wrote a column saying that President Clinton had given a gift of hope to victims of Parkinson's, Alzheimer's disease, diabetes and prenatal disorders by lifting the ban that Presidents Reagan and Bush had imposed on federal funding of fetal tissue research. But, I wrote, Clinton then "dashed that hope by cutting the funding" for research—\$9 million from the budget of the National Institute of Neurological Disorders and Stroke and \$4 million from the National Institute on Aging. I quoted Samuelson as saying that Parkinson's and Alzheimer's research were "sacrificial lambs to pay for cures for AIDS and cancer while trying to reduce the deficit."

Indeed, in his first budget as president in 1993 Clinton had asked for \$225 million more for AIDS research, to bring the total to \$1.3 billion, and \$130 million more for cancer, for a total of \$2.1 billion. According to what came to be known as Samuelson's "disparity chart," NIH then was spending an average of \$1,000 a year on research to help each of the nation's 1.3 million HIV/AIDS victims. For each of 8 million cancer victims, NIH spent \$260, while 4 million Alzheimer's patients got just \$54 each, and 1 million Parkinson's victims \$26 each. In this column I said that "a close relative of mine" had Parkinson's.

The next step in my education came just a few weeks before the White House party, at a big dinner honoring Abe Pollin, owner of Washington's pro basketball and hockey teams, whose wife, Irene, was Milly's friend and former social work colleague at the Neurology Center. The Pollins arranged for us to sit with Abe's political adviser, Washington health lobbyist Terry Lierman, who proceeded to completely demystify medical research politics. Lierman told Milly and me that diseases were allocated research money based on the clout of their advocates—in the White House, in Congress, in the media and public opinion, and within NIH and the scientific community. Disease researchers who were receiving the most money one year had the best chance of getting more the next year, sometimes regardless of the scientific merit of their proposals. Parkinson's was bringing up the rear, he said, and probably would stay badly funded unless the whole of NIH got a major boost in funding.

Lierman also revealed to us that Bill Clinton, though he was helping AIDS and breast cancer research, was giving short shrift to every other disease studied at NIH, not just neurological diseases. This news stunned me, but it had credibility because Lierman was a Democrat. It was news that the public was unaware of—something I could definitely write about, I said.

Now, as we moved slowly through the receiving line that snaked from the cavernous main-floor receiving room of the White House, down a stairway and through a ground-floor hall-



PARKINSON'S PATIENTS MICHAEL J. FOX AND MARY TYLER MOORE LAST FALL AT A SENATE HEARING.

way, Milly rehearsed what she planned to say: "Mr. President, I love the two of you. I think you're great. I tell Morton that all the time. I tell him to write nice things about you. I want to say, I have Parkinson's disease, and there isn't enough money being spent on research. I hope you'll do something about that."

She repeated the speech two or three times. I was ready to cite some figures from Samuelson's disparity chart and tell the Clintons that Parkinson's was a disease that could be conquered soon with an extra effort.

When we reached the Clintons and were introduced by a military aide, Milly started, "Mr. President, I want to tell you something. I have Parkinson's disease..." Then she lost track. She turned to me, "Morton, what do I want to say?"

I, even less articulate, hiked my thumb into the air and blurted: "Increase brain research." Clinton just nodded, but Mrs. Clinton chimed in, "Oh, wait till we pass health reform. We're going to do a lot!"

You move on fast in these receiving lines. That's all we got to say. I felt embarrassed that I'd been so frozen-headed. But I muttered to Milly as we walked on, "Well, you've just been lied to by the first lady of the United States."

There was nothing in Mrs. Clinton's health care reform plan for neurological research, or much of anything at all for medical research. To make matters worse, the Clinton budget released the following February contained a mere 0.5 percent net increase for neurology after inflation. For NIH as a whole, Clinton requested a 4.7 percent increase, only 1.7 percent after inflation.

For the next year, fiscal 1995, Clinton was proposing less of an increase than had been enacted for the previous year, with the biggest increase going for just two favored diseases—breast cancer and AIDS. Clinton had angered the gay rights movement, which supported him in the 1992 campaign, by failing to lift the ban on gays serving in the military, instituting the policy of "don't ask, don't tell" instead. However, in an apparent effort to mollify gays, he increased the AIDS research budget by 20 percent in his first year in office. In the meantime, women's groups were legitimately angered that breast cancer research was underfunded, and Clinton responded with a 33 percent increase in fiscal 1994 and another 28 percent the following year.

More than one conservative Republican we visited looked at Samuelson's disparity chart, expressed sympathy with our cause, and declared, "We can get the money for Parkinson's from AIDS." A few members added, "Preventable disease," referring to AIDS. I confess, I did not argue with them.

FOR FOUR YEARS a newly energized Parkinson's community rallied around the Udall bill, named after Mo Udall, the longtime chairman of the House Committee on Interior and Insular Affairs who was diagnosed with Parkinson's in 1979. One celebrated effort was mounted by the Tucson real estate investor Bob Dolezal to get Arizona's senior senator, Republican John McCain, to support the bill. Diagnosed with Parkinson's in November 1992, Dolezal first wrote to McCain in 1993. He got back a form letter thanking him for his views. He shifted his attention to Rep. James Kolbe (R-Ariz.) and gained his support rather eas-

CONTINUED ON PAGE 25

ily. Then he turned back to McCain. His mail and phone calls started getting answered—impatiently—by a particular McCain aide. Dolezal bombarded him with correspondence.

Finally, in March 1996, Dolezal exploded in an e-mail that ended: "One can reach one of three conclusions: The NIH is stonewalling and doesn't want [Parkinson's funding] data made public, that the request of the senior senator from Arizona has been cavalierly disdained by NIH; or that the senior senator from Arizona never seriously pursued this matter, and really doesn't give a damn. Which one gets your vote?" This outburst had consequences, short- and long-term. Somehow word got back to the University of Arizona, which promptly severed connections (since restored) with the Tucson chapter of the American Parkinson's Disease Association, which Dolezal headed. That response not only inspired Dolezal to launch a statewide campaign in Arizona's Parkinson's community to work on McCain but persuaded him to fly to Washington to visit McCain personally.

He took along Brad Udall, Mo's son and lookalike, who was a board member of PAN, and Mary Helen Davila, a Parkinson's activist and sufferer from Phoenix. Davila told McCain what Parkinson's was doing to her—and cried. Dolezal launched into the Parkinson's case. McCain interjected that he did not like to earmark for specific diseases. Dolezal kept spouting statistics and arguments.

Suddenly McCain put up his hand. "Okay, that's enough. I'll co-sponsor the bill." This time Dolezal began crying. "It was one of the greatest experiences of my life," he told me.

When Oregon's Mark Hatfield retired in 1997 after 30 years in the Senate, it became crucial for the Parkinson's movement to find an influential Republican to carry the cause. Sen. Paul Wellstone of Minnesota, both of whose parents had died with Parkinson's, was the lead Democrat. In January 1997, Dolezal wrote to McCain, suggesting that it would be especially appropriate for him to take the lead given his friendship with Mo Udall. Within a week Dolezal got a call from McCain's office with the word: The senator would do it.

On September 3, 1997, McCain and Wellstone offered the measure as a floor amendment to the annual appropriation for the departments of Labor, Education, and Health and Human Services. There was a brief floor debate in which McCain

Even though it was part of an appropriations bill, the Udall bill did not guarantee one cent more would be spent on Parkinson's research.

said that "there is a gross inequity here that needs rectification," citing figures from Samuelson's disparity chart. The vote to approve the Udall bill was overwhelming, 95-3. However, the Senate fight was not yet over. The next day, antiabortion Sens. Dan Coats (R-Ind.) and Don Nickles (R-Okla.) planned to amend the Udall bill with language reviving the Reagan-Bush ban on federal funding for fetal tissue research. Samuelson and PAN's policy coordinator, Mike Claeys, were at PAN's office in Santa Rosa, Calif., and from there spent all night soliciting statements from scientists on the importance of the research and faxing material to friendly senators in Washington. The next day the Coats-Nickles amendment was defeated, 60-38.

The Udall bill survived a House-Senate conference on the Labor-HHS appropriation. Its passage was hailed by Parkinson's advocates as a moment of triumph. Indeed, we were invisible no more.

But the passage of the Udall bill did not guarantee that one cent more would be spent on Parkinson's research. Even though it passed as an amendment to an appropriations bill, the Udall bill was not an appropriation; it simply authorized NIH to establish a Parkinson's-related research program.

Where should the money come from? My first instinct—based partly on my knowledge of the funding disparities, and partly perhaps on prejudice—was to take it away from HIV/AIDS. It struck me as deeply unfair that the government was spending something like 40 times the amount per victim on AIDS as on the disease that was killing my wife.

In 1996 I began working on a PBS documentary, "The Politics of Medicine," which ran on the network in October 1997. One of the first people I interviewed was the AIDS activist (and patient) Gary Rose, who had once attacked PAN over the disparity chart, calling it "AIDS-phobic." When I asked him about that, he accused me and PAN of telling Congress that the plight of AIDS victims was their own fault, that the money should be given to Parkinson's. He said that, after watching so many friends die, he found that argument repulsive. And to put the blame on the victim, whether the disease is HIV or lung cancer, is wrong.

"Most people don't have a choice about getting HIV-infected," he said. "I didn't have a choice. To say to someone, 'You

should have worn a condom,' just think about that: If HIV were a disease primarily of middle-aged, white heterosexual men . . . you tell the entire community . . . 'You have to wear a condom for the rest of your life. Period. And if you don't, it's your own fault if you die.' That would not wash if you were telling those people that . . . Human beings like to have sex . . . and they like it to be natural, not negotiated."

As I sat across from him, I felt myself getting furious at the implication of his argument. I burst out at him: "Well, as a citizen and as somebody who's married to someone who has Parkinson's, the way I look at it is, I see a community that has a preventable disease. It has mobilized itself very carefully, using Hollywood and the gay community, has impacted Congress, has gotten an enormous amount of money spent on it . . . And the consequence of this is that an enormous amount of money . . . has been devoted to this group's disease . . . The diseases that I care about are defunded, underfunded. Why am I wrong?"

He burst back, underscoring how AIDS had ravaged "homosexuals, drug addicts, poor black people . . . If the most condemned sections of American society can pull together and do the remarkable and miraculous thing that we've done . . . We didn't have any power. We didn't have any money. We had nothing. We had *nada*. No one would talk to us. If we can build that out of those garbagey tools, I don't understand how anybody in good faith can now come after us and say, 'You really don't deserve your success. You could have stopped it. You can stop it now . . .'

"I'm just incredibly offended by being condemned for success that has cost me every person I cared about in my entire life. This epidemic has decimated my entire peer group. Everybody that I've worked with, cared about, lived with. And out of that pain, we've developed a movement, a process where we could cure this disease in 10 years. And I have to have somebody coming after me and saying, 'You don't deserve that? Give some of it to us.' I'm sorry, I don't think that's moral."

He finished me off with a challenge: "Are you going to stop working in television and become a full-time Parkinson's advocate? When you've done that, when thousands of other people, including people with Parkinson's, have done that, have given up your lives

to find a cure, then you come back to me and say, 'You have to give up some of yours.'"

It was a powerful rebuttal, but Rose made an even stronger argument that convinced me that there was no future in trying to rob AIDS to help Parkinson's. Even if the money were cut from AIDS research, he said, it wouldn't go to Parkinson's; it would go to the next most powerful disease. He cited breast cancer research, which was being pushed by a powerful coalition of women's groups and the White House, and diabetes, at the time the favored disease of Republicans because House Speaker Newt Gingrich's then-mother-in-law suffered from it. I knew instantly that Rose was completely correct and that the funding definitely had to come from somewhere else.

THE OBJECT of the Parkinson's movement's post-Udall lobbying was to get Congress to actually appropriate \$100 million for Parkinson's research—or to write language as close to a directive earmark as we could persuade congressional leaders to accept. Other diseases kept getting them. One year Gingrich and then-White House Chief of Staff Erskine Bowles, whose child suffers from juvenile diabetes, quietly put an extra \$300 million for diabetes research into a final budget agreement. Another year Ted Stevens (R-Alaska), chairman of the Senate Appropriations Committee, became irritated that prostate cancer was getting less attention than breast cancer and added \$50 million for that. In truth, Parkinson's also benefited from inside action when Rep. Joe McDade (R-Pa.), a member of the House Appropriations Committee who has since retired, was diagnosed with Parkinson's in 1996 and created a \$25 million fund for neurotoxin disease research in the Defense Department.

In 1998, in an effort to get a \$100 million earmark for Parkinson's in the NIH budget, I went with Samuelson to talk to McCain. We met McCain in an ornate room just off the Senate floor. He listened as we explained that NIH, despite the Udall bill, was refusing to significantly increase Parkinson's funding and probably would not do so without a command from Congress. Would he co-sponsor a floor amendment with Wellstone to write \$100 million into the Labor-HHS appropriations bill? McCain became irate. "This is earmarking," he said. "This is pork. I have

spent my entire congressional career fighting this sort of thing. If you're looking for somebody to do this, I'm not your guy."

Running for the Republican presidential nomination in 2000 and eager to retain the support of abortion opponents, McCain later apologized for his vote lifting the ban on fetal tissue research and came out against federal funding of highly promising research using stem cells derived from leftover embryos at fertilization clinics.

On January 31, 2000, the day before George W. Bush lost the New Hampshire primary to John McCain, I slipped into a makeup room at Manchester TV station WMUR, where Bush was cleaning his face after a Fox News appearance. He knew who I was because I'd interviewed him for a profile in *Reader's Digest* the year before. I said, "Can I write you a letter about my favorite cause?"

"What cause is that?" he asked.

"Doubling the NIH budget," I started. "It's..."

"I'm for it," he said. "I've talked to Connie Mack about it. I told him I'm for it. It's the right thing to do."

I said, just as inarticulately as I'd done at the Clintons' Christmas party, "Think brains."

"Brain cancer?" he asked.

"No, neurology," I said. I made a borch of my speech. "Great things are happening," I said. "Neurodegenerative factors... No, I mean, something called neural growth factors... Great implications for Alzheimer's, ALS [amyotrophic lateral sclerosis], stroke, Parkinson's. Great things are happening..."

I finished with my favorite political argument for Republicans: "Republicans in Congress have been increasing NIH by 15 percent a year, ramping up to double. They never take credit for it."

"They don't know what they are doing," Bush said.

"Al Gore only wants to double the cancer budget, not the whole," I volunteered, hoping he'd try to trump Gore and make doubling the NIH budget a centerpiece of his campaign.

"No," Bush said, "I'm for doubling the whole—what, over 10 years?"

"No," I said, "five. They can do it over five. NIH can absorb it over five."

"Okay, I'm for it."

Besides writing columns, I kept nagging Bush's political and issues staff to get the candidate to make a major speech proposing a doubling of funding for medical research.

In September 2000, Bush came out with a rousing statement: "As president, I will

fund and lead a medical moonshot to reach far beyond what seems possible today and discover new cures for age-old afflictions... Our government will promote medical advances with new resources and new resolve."

Bush's campaign staff produced a position paper that was thorough and sophisticated about the hopes that medical research might fulfill reasonably soon, including gene therapies for cystic fibrosis, Huntington's disease and some forms of deafness, and new drugs that strangle the blood vessels that feed tumors. The language on Parkinson's was pure music: "The world's leading neuroscientists have declared that Parkinson's can be cured within 10 years—and what's learned in the process can help cure Alzheimer's, Huntington's and other neurodegenerative diseases." Bush promised to finish the job that Sens. Mark Hatfield, Arlen Specter (R-Pa.) and Tom Harkin (D-Iowa) and Rep. John Porter (R-Ill.) had started in fiscal 1998, doubling the NIH budget to \$27.5 billion by fiscal 2003. He promised to increase spending over 10 years by \$67 billion.

Even though his September speech was eloquent, the message was never repeated in the campaign, indicating it was not a core part of his program. And he didn't promise to redouble the research budget in the five years after 2003. The \$67 billion he campaigned on would not pay for redoubling over 10 years.

IN JANUARY 2000 Michael J. Fox announced that he was leaving his TV show, "Spin City," to devote himself to conquering Parkinson's. This produced a huge burst of publicity—and an invitation from Hillary Clinton to sit in her box when President Clinton delivered his State of the Union message on January 27. I was sitting in Chicago's O'Hare Airport en route from the Iowa presidential caucuses. My cell phone rang. It was Fox. He said he was inclined to turn down Hillary's invitation. It would look like an endorsement of her senatorial candidacy, he said. I was a little startled, but in an instant I realized that he had shrewd judgment. I said, "You are absolutely right. All you'll get out of it is five minutes of face time with Hillary, if that. She'll promise you something for Parkinson's, but she'll lie just like Clinton did to Christopher Reeve. You'll just get used." (Reeve had visited the White House and was promised \$10 million extra for spinal cord injury research. But it never materialized.) Without accepting my invidious analysis, Fox skipped the State of the Union.

In the fall, just before the 2000 election, Fox wrote an op-ed column in the New

York Times pointing out the differences between George Bush and Al Gore on the issue of embryonic stem cell research—Bush remained against it, Gore was for it—and urging that the research be allowed to continue in order to save lives. When Bush became president, he hinted that he might issue an executive order banning federal money for stem cell research. As it turned out, Bush had heard from numerous disease advocates—including Sen. Connie Mack (R-Fla.)—urging him not to stop the research. And he did not, ordering a study of the issue instead. The issue is still pending.

Fox wants to tell President Bush that he could be the president who presides over the conquest of Parkinson's. The request for a meeting is also still pending.

EVER SINCE MILLY was diagnosed with Parkinson's, the nation's leading neurologists have been saying that this disease could be cured within 10 years. They still say that, but Milly's time is running out.

She is confined to a wheelchair. It's progressively harder for her to eat solid foods. Four times, I have had to perform the Heimlich maneuver to prevent her from choking to death. Often she has trouble even drawing liquids up through a straw. She can barely speak. Her voice has no volume and she has difficulty forming intelligible words. Her mind, however, is sharp. We communicate mainly through portable computer, though she has difficulty punching the right keys. She is inexorably becoming a prisoner trapped in her own body.

I do not know how our love story will end, or when. Some days, she says she does not want to live like this any longer and, when the time comes, will refuse a feeding tube and starve herself to death at a hospice. Other times, she says she will agree to have a tube implanted in her stomach—reserving the right, however, to have it removed when she feels utterly trapped and life becomes intolerable.

I pray every day that a medical miracle will save her. But it does not seem to be forthcoming. I am losing Milly. But when I lose her, if I lose her, our story will not end. Memory will survive. I remember the restaurant where we first met, the raincoat she was wearing the moment I knew I had fallen in love with her, the soft couch where we first made love, the smell and taste of her that I became addicted to for life. And 33 years of marriage—our fighting, our children, her steel, her generosity. Her courage. I will keep working to end Parkinson's disease on her behalf, and I will hug her in my heart forever. ■

Edward Long, Ph.D.
Senior Vice President, Congressional Relations

Edward Long joined Capitol Associates in 1995 as Vice President, Congressional Relations, where he works with appropriations and public health issues.

For 13 years, Edward Long worked in the U.S. House of Representatives and the Senate. From 1993 to 1995, he served as the Majority Staff Director of the U.S. Senate Labor-HHS-Education Appropriations Subcommittee. In addition to overseeing the budgets of the Departments of Health and Human Services, Education, and Labor, Mr. Long's principle responsibility was preparing the budget for the National Institutes of Health. Just prior to joining the Appropriations Committee, he served as the Legislative Director to U.S. Senator Tom Harkin (D-IA).

From 1983 to 1990, Mr. Long was the chief foreign policy assistant, first to the late Congressman Ted Weiss (D-NY), a member of the House Foreign Affairs Committee, and later to Senator Harkin. While serving Senator Harkin in this capacity, Mr. Long was responsible for all foreign aid appropriations, including monitoring development assistance programs.

Mr. Long received his Ph.D. from the University of California at San Diego. In 1982, he was awarded a Congressional Fellowship from the American Historical Association.

Michael Claeys
The Michael J. Fox Foundation for Parkinson's Research

Michael Claeys was named research policy coordinator of the Foundation in March 2001. He was involved with the launch and early activities of the Foundation as senior policy coordinator for the Parkinson's Action's Network (PAN). In his five-year tenure with PAN, Claeys conducted grassroots advocacy and direct federal lobbying on behalf of the Parkinson's community.

Claeys earned a B.A. in political science from California Polytechnic State University, San Luis Obispo, after which he served five years in legislative staff positions in the United States House of Representatives.



ROBERT O. BOORSTIN, Vice President

Bob Boorstin has been Vice President of Greenberg Quinlan Rosner since August, 1999. Since joining the firm, Boorstin has combined his experience in political campaigns, communications and foreign affairs to assist a wide variety of private and public sector clients. Overseas, Boorstin has worked on political campaigns - including the Israeli Labor Party, the Viennese Social Democrats, and the British Labour Party - as well as corporate telecommunications and high technology. He also played a major role in the firm's landmark 12-nation "People on War" project for the International Committee of the Red Cross.

In the United States, Boorstin has done corporate, non-profit and political work. He has focused on health care, working with the National Mental Health Awareness Campaign to shape its campaign against stigma; conducted similar research on substance abuse for the Lewin Group; and advised firms exploring the provision of health services via the Internet. In the 2000 general election, he oversaw the qualitative research that GQR conducted for the Gore/Lieberman campaign. He has also worked with the Vietnam Veterans of America Foundation, carrying out research on nuclear disarmament and justice issues.

Prior to coming to GQR, Boorstin served for seven years in the Clinton Administration, holding high-level positions in the White House, the State Department and the Treasury Department.

From 1997-1999, Boorstin served as Senior Advisor to Secretary of the Treasury Robert E. Rubin. In that position, Boorstin counseled the Secretary on political and communications strategy for a wide range of domestic and international issues, including the Asian financial crisis and emerging market economies. Boorstin previously served for two years as Senior Advisor to Secretary of State Warren Christopher, focusing on U.S. relations with Asia and Africa.

Boorstin, 41, joined the Clinton Administration in 1993 after working as Deputy Communications Director for the 1992 Clinton/Gore campaign. At the White House, he served as Senior Director for Speechwriting at the National Security Council from 1994 to 1995. His assignments included the 1994 State of the Union speech, the 1994 Israeli-Jordanian peace agreement, and the first remarks delivered by an American President in the former East Germany. Prior to assuming that position, Mr. Boorstin was Special Assistant to the President for Policy Coordination, with a focus on health care reform.

Boorstin previously worked for a number of national newspapers and magazines. From 1985 to 1987 he was a reporter for *The New York Times*, where his assignments included the United Nations desk and local and state affairs. He has also contributed to *Newsweek*, *The Washington Post*, and WGBH public television. Boorstin's previous experience in political communications include the 1988 and 1984 Democratic presidential campaigns and corporate consulting for the Sawyer Miller Group of New York.

Boorstin received his B.A. in history, magna cum laude, from Harvard College in 1981. At Harvard, he was Editor-in-Chief of *The Crimson* and studied United States-East Asian relations. As a fellow of the Keasbey Foundation, Boorstin attended King's College, Cambridge, where he wrote about U.S. relations with China and the Soviet Union. He received his M. Phil. in International Relations in 1983.

Since 1987, when he was diagnosed with manic depressive illness, Boorstin has been an outspoken advocate on behalf of people with mental illness. He has addressed medical professionals, families, and patients across the country, worked closely with leading advocacy groups, and is a member of the National Advisory Committee to the National Institute of Mental Health.

Lynn Fielder
Planned Parenthood

Lynn Fielder has had a varied career path that has provided her with many insights into the processes for shaping US policy and public opinion. Lynn began her career in Washington DC, working for the Congressional Research Service division of the Library of Congress. She then worked for the Agency for International Development where she was able to pursue her passion for working with underserved populations.

Lynn returned to California to get a Masters degree each from Stanford and Berkeley – an MA from the Food Research Institute at Stanford and a Masters in Public Health, Maternal and Child Health from UC Berkeley.

Lynn then chose to align her professional goals with her convictions and began working at Planned Parenthood in 1990. Lynn has helped lead the organization through 11 mergers and managed its ten-fold growth, helping Planned Parenthood Mar Monte become becoming the largest affiliate in the country. She serves as Vice President of Services, External Affairs

As her job has grown, so has her family with a supportive husband and a wonderful nine-year old daughter. During this decade Lynn also faced new challenges that she as she was diagnosed with Parkinson's Disease. Lynn's experience with the media, political advocacy and even familiarity with the controversy associated with reproductive rights has positioned her well for the challenges and politics now plaguing finding a cure for Parkinson's.

In addition to serving on the Board of the Parkinson Alliance, Lynn has sponsored fundraising events and she uses every media opportunity to educate regarding the need to fund and find a cure. Lynn's entire family is committed to this cause with her 9-year-old daughter Maya becoming a powerful and eloquent advocate as well.

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Opinion

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MY VIEW

By Lynn Felder



COMPETING human cloning bills will soon be debated and voted upon by the U.S. Senate. Many people do not realize that embroiled in this debate is not just futuristic reproductive cloning (producing babies genetically identical to one parent), but therapeutic cloning as well.

Therapeutic cloning, which scientists call somatic cell nuclear transfer, produces stem cells, not people. The distinction is critical to the future of millions of Americans who are battling incurable, life-threatening diseases.

I am a 40-year-old woman, mother and now an activist. I have Parkinson's disease, and my future is at stake in that vote. People motivated by fear, ignorance or worse are attempting to bury the health

and hopes of people like me by creating the false impression that many factions of society are opposed to this vital research.

Support for therapeutic cloning is broad among those who understand it, because the promise that therapeutic cloning holds is almost beyond imagination. Curing neuro-degenerative diseases, spinal cord injuries and diabetes is just the beginning of the potential of somatic cell nuclear transfer.

Somatic cell research, like recombinant DNA 15 years ago, is tremendously promising. In this process, scientists replace the nucleus of an unfertilized egg cell with material from the nucleus of a "somatic cell" (a skin, heart, nerve or any other non-germ cell).

What results is cloned tissue, and doctors believe it would eliminate the rejection that often occurs with organ transplants.

Stem cell research has been strongly endorsed by a high-level

committee of the National Academy of Sciences, all major patient advocacy groups, Nobel Prize winners, and medical researchers.

With full support and sufficient funding, scientists believe that stem cell research could usher in a new era of health within the next five to 10 years.

Five years will be in time for me and perhaps millions of other people with debilitating diseases; 10 years will have a profound positive impact for many, but for me it will probably be too late.

Sen. Sam Brownback has introduced a bill (S. 858) that would not only ban reproductive cloning, but also therapeutic cloning and impose severe criminal and civil penalties on scientists who conduct somatic cell nuclear transfer research.

On the other side are bills sponsored by Sens. Edward Kennedy and Dianne Feinstein (S. 1758) and Tom Harkin and Arlen Specter (S.

Cloning research: It could save your life

1933) that would ban reproductive cloning but allow somatic cell nuclear transfer research to proceed, with appropriate controls, to cure life-threatening diseases.

Supporters of the Brownback bill, the very familiar opponents to most forms of stem cell research, are employing their usual tactics.

Using hyperbole and fear, they are promoting notions of renegade engineered human clones, created by genetic manipulators who are driven by avarice and greed.

The Brownback bill exemplifies the dangers of using fear of this new world to suppress and punish science. We can't undo our cellular manipulation, we can't undo the spitting of the atom, we can't even get the toothpaste back in the tube.

But how we thoughtfully manage our discoveries is the duty of a democratic society. It is also our responsibility to not discard the "good science" when faced with

new discoveries.

Many people are unaware of the extreme measures in the Brownback bill. Brownback seeks to institute a five-year moratorium on all "cloning" and goes so far as to legislate imprisonment of 10 years for someone such as myself if I were to travel abroad for somatic cell treatment for my Parkinson's Disease.

The irony of being potentially freed from the imprisonment of this disease but being thrown in prison by my government is almost too much to bear.

Denying Americans legal access to effective medical therapies is inappropriate, immoral and inhumane. Please let us not further confuse this already complex issue or fail to speak up — the stakes are too high and we are wasting precious time.

Lynn Felder serves on the board of The Parkinson Alliance (www.ParkinsonAlliance.net), and is the president of medical service for Planned Parenthood Mar Monte in San Jose.



Dear Senator

I am learning about our government. Since what you do makes a big difference, I wanted you to see what I have to say about reaserch that will help my mom. I will come and say it to Congress if it will help.

Maya Fielder
2142 Bryant st.
Palo Alto California 94301
(650) 322-3268

Help Find a Cure for Parkinson's Disease

My name is Maya Fielder and I am 9 years old. I live in Palo Alto California and I am in the 4th grade at Escondido School.

When I was a little baby my Mom found out she had Parkinson's Disease. I was with my Mom, but I don't really remember when the doctor told her she had a bad disease that gets worse and worse and doesn't have a cure. I know that now there are lots of things I can't do with my Mom and sometimes I feel like I have to take care her instead of her taking care of me.

I learned that Parkinson's Disease is when your brain doesn't produce enough dopamine. Dopamine is important because it tells your body how to move. My Mom's body tremors and she can't write things down or if she does no on can read it, not even her. She gets disabled to walk so she rides my scooter around the house (I'm not allowed to ride in the house though). And sometimes she can't even walk until her medicine starts working so my Dad and I get things for her. She takes tons of pills every day but the medicine or the disease causes more problems for her so my Mom tries new medicines and different things a lot to try to get better.

Our whole family works hard to help find a cure for Parkinson's. My mom talks about Parkinson's to the newspapers or on the news whenever she can and sometimes my name or picture is shown too! We had a charity art show at our house and Uncle Dan's art raised a lot of money. I even sold a painting and all the money went to Parkinson's research. My mom said that if researchers got enough money from Congress and from regular people that scientists could find a cure in 5 or 10 years. That would be good because I won't be a grown-up yet and my Mom will get better and we could go iceskating together.

But now we have a big problem. I heard President Bush say that all cloning research has to stop. My Mom was really upset because she said the President and some people in Congress want to stop researchers from finding a cure for Parkinson's and lots of other diseases that make millions of people sick. I don't get it.

One part of the Pledge of Allegiance says 'Liberty and Justice for all'. I don't think the government is giving us much liberty or justice - at all!

People are scared of the kind of cloning that would make new people (reproductive cloning). But what's so scary about finding a cure for my Mom?

That kind of cloning is called therapeutic cloning and doesn't make people or kittens or anything like that - it would just help my Mom's brain work again like it is supposed to.

I think that the people who make the laws should make rules so scientists won't do bad things with research. But can't they still be allowed to do the good research? My mom said the Brownback bill that is being voted on Congress soon wouldn't allow scientists to do the good kind of research that would help her. She also said that this law wants to put people like her in jail if they try to get cured. That's just dumb! My Mom isn't doing anything wrong by just trying to get well.

I thought I might want to be a scientist when I grow up but I don't think so any more. I just want to find a cure for my Mom. I guess I'll become the President of the United States so that I can make good laws that help people and cure diseases. I'll let scientists do their work and make all kinds of new discoveries.

I know that this isn't the most important thing for everyone. But I think that if someone in your family was sick and you were worried, that you would do everything you could to help them get better. You wouldn't make laws so that a cure would not be found and you wouldn't put them in jail.

Please help find a cure for my Mom and everyone else that needs one instead of making it harder. I'm doing as much as I can do to help my Mom and other people too (when I'm not in school or doing sports or playing violin, but Mommy says that helps her too). This is really important to a lot of people especially kids. So for all of us and the people we want to help, thank you if you can make things better

Dr. Patricia D. Hawkins is both a licensed clinical psychologist and licensed clinical social worker with more than 30 years of experience in the design, development, implementation and administration of comprehensive, community-based medical/psychosocial human service programs.

Dr. Hawkins has particular expertise in the areas of HIV/AIDS, substance abuse, women's health, gay, lesbian, bi- and transgendered health and mental health issues, mental and/or physical disability, vocational rehabilitation, and program development for historically underserved populations.

Gail Pressburg, a Senior Fellow at the Center for Civil Society, has been a social change activist for 25 years. Prior to her assignment at ICS, she was director of the Center for Israeli Peace and Security of Americans for Peace Now; Executive Director of the Foundation for Middle East Peace; and a Staff Director at the American Friends Service Committee.

Daniel Weiss
M&R Strategic Services

Daniel J. Weiss, Senior Vice President, works with national environmental organizations to defend critical environmental protections. He coordinates paid and earned media, grassroots activities, and other efforts to educate the public and press about energy policy, public lands protection, clean air and other issues.

From 1985 to 2001, Weiss worked at the Sierra Club, most recently as national political director during the past four election cycles.

Dan has Master of Public Policy and Bachelor of Arts degrees from the University of Michigan. Dan is married to Sherry Ettleson, and has two daughters and a son.

Bill Franklin

Bill Franklin is an active National Parkinson's Disease Advocate with a strong business background. He has a BS and an MBA and has held responsible positions in information technology, marketing/sales, and strategic business planning for Fortune 500 companies. His current focus is on integrating a creative action oriented business perspective into curing PD. Bill is working with a number of organizational teams to make it happen.

Greg Wasson

Professional and Educational

- Born Dec. 18, 1951, in Oakland CA
- Raised in North Bay town of Vallejo, California, where father was employed at Mare Island Naval Shipyard
- Graduated Vallejo High School in 1970
- Graduated from University of California at Berkeley, cum laude, 1974 majoring in U.S. history
- Tax Auditor and Taxpayer Service Representative with IRS - 1974 to 1980
- Graduated University of California Hastings College of the Law 1983 (member: Order of the Coif, Thurston Society)
- 1981 to 1984: Law Clerk and Attorney for Lynch, Loofbourow, Helminstine, Gilardi and Grummer (insurance defense litigation)
- 1984 to 1988: Corporate Counsel to Industrial Indemnity Co.
- 1988 to 2000: Senior Attorney Editor -- Westgroup Law Publishers; retired on disability Jan 2000

Parkinson's Disease and Advocacy History

- 1995 - diagnosed with Parkinson's Disease
- January 2000 - left employment due to disability caused by Parkinson's disease
- 1998 - organized local Parkinson's support group in Oakland CA - still attends
- Active member of Massachusetts General Hospital Neurological Web Forum (Braintalk Communities) since 1998
- Began volunteer work with Parkinson's Action Network in 1999
- Participant in clinical studies at Parkinson's Institute, Palo Alto, and UCSF, San Francisco
- Spring 2000 -- Began consulting with Michael J. Fox concerning Foundation Website; contributed several essays to "Living With Parkinson's" section. Occasional consultant to MJFF concerning website content and structure. Recently co-wrote FAQ section for Newly Diagnosed and Caregivers for new MJFF website with partner Ann Campbell.
- Attended 2000 PAN/MJFF Public Policy Forum
- Fall 2000 -- Joined People Living With Parkinson's, Inc -- Currently Leader of Advocacy Team
- February 2001 -- Authored and promoted online Stem Cell Petition to President Bush which was personally delivered in hard copy with comments by signatories to Mary K. Mantho, Chief Policy advisor to Health and Human Services Secretary Tommy Thompson. Petition gained over 20,000 signatures.
- April 2001 -- Keynote Speaker (with Ann Campbell) at annual symposium sponsored by Hawaii Parkinson's Association.
- 2001-2002 -- Worked with PAN to develop e-based Grassroots Advocacy Network. Currently State Coordinator for No. California of Grassroots Advocacy Network.

Ann Campbell

Ann Campbell, diagnosed with Parkinson's in 1995, at the age of 37. Children's book author, former New York children's book editor and librarian. Currently living in California. Active in PAN grassroots and People Living With Parkinson's. Co-author with Greg Wasson of Questions and Answers for Newly Diagnosed and for Caregivers on the Michael J. Fox website.

Jeff Martin
Shea & Gardner

Jeffrey C. Martin is 48 years old and lives with his wife and two daughters in Rockville, Maryland. He has practiced law with the Washington, D.C. law firm of Shea & Gardner since 1980, except for a break in 1991-92 when he served as General Counsel of the U.S. Department of Education.

Jeff splits his time between his law practice and his role as a Senior Vice President of retailer Saks, Incorporated, where he handles government relations, compliance and special projects.

Diagnosed with Parkinson's Disease in early 1998, Jeff is also quite active in working with the Parkinson's community to advocate increased funding and improved management of the biomedical research necessary to cure Parkinson's Disease and other neurodegenerative diseases. He serves on the board of the Parkinson's Action Network and as a member of the NIH's Parkinson's Disease Implementation Committee.

In his spare time, Jeff can usually be found working in his garden.

John R. Marler, M.D.
National Institute of Neurological Disorders and Stroke

John R. Marler, M.D., a board certified neurologist, is Associate Director for Clinical Trials at the National Institute of Neurological Disorders and Stroke. He has been Program Director for clinical research in stroke since 1984. He was project leader for the NINDS TPA Stroke Trial and the NINDS Master Agreement for Cerebrovascular research. He has administered most NIH-sponsored clinical trials in stroke. He completed his neurology residency training at Mayo Clinic in Rochester, Minnesota and graduated from West Virginia University Medical School in Morgantown, West Virginia. Prior to medical school he worked as a computer systems engineer and a cabinetmaker, taught statistics, and was Vice-President of a structural steel detailing company. He attended Bowdoin College in Brunswick, Maine.

Bernard Ravina, M.D.
National Institute of Neurological Disorders and Stroke

Dr. Ravina is a program director in the clinical trials cluster. Dr. Ravina received his BA in psychology from Columbia University in 1989 and his MD from Johns Hopkins in 1995. He completed a neurology residency and then fellowships in movement disorders and epidemiology at the University of Pennsylvania. Dr. Ravina's main area of interest is clinical trials and experimental therapeutics for neurodegenerative disorders.

Karl Kieburtz, MD, MPH

University of Rochester School of Medicine & Dentistry

Karl Kieburtz, MD, MPH, is Professor of Neurology and Community and Preventive Medicine at the University of Rochester School of Medicine and Dentistry in Rochester, New York. His primary clinical and research interests are in the treatment of neurodegenerative disease affecting the basal ganglia, particularly Parkinson's disease, Huntington's disease, and HIV related neurologic disorders. He has been an active participant in the research activities of the Parkinson Study Group since 1989, and directs the Coordination Center for this and other multi-center academic consortia, including the Huntington Study Group and the Neurologic AIDS Research Consortium.

Ross L. Stein, PhD

Director

Laboratory for Drug Discovery in Neurodegeneration

During his career, Dr. Stein has made contributions in the areas of mechanistic enzymology and drug discovery. Specifically, he has contributed to the understanding of mechanisms of catalysis of a large number of enzymes, including: elastase, stromelysin, prolyl isomerase, the proteasome, ubiquitin C-terminal hydrolases, signal peptidase, g-glutamyl transpeptidase, and penicillin binding proteins. The knowledge gained from these studies has been applied to the design of inhibitors of these enzymes and, in several cases, to the development of new therapeutics for human disease. For elastase and the proteasome, these basic mechanistic studies contributed in a direct way to the development of a drug that was in clinical trials in the early 1990's for cystic fibrosis (i.e., elastase inhibitor) and a drug that is currently in Phase II trials for cancer (i.e., proteasome inhibitor). As a manager, Dr. Stein built and ran research departments in both pharmaceutical and biotech companies. At Merck, he built the Department of Enzymology which contributed broadly to many projects that had enzymes as their therapeutic targets. Several of these projects resulted in drugs that went into human clinical trials. At ProScript, he was the company's first scientist and helped build the research department to about thirty scientists. As head of Biochemistry, Dr. Stein managed a staff that worked on the development of assays and elucidation of mechanism for enzymes of the ubiquitin-proteasome pathway. The work of this group of scientists was instrumental in the development of a proteasome inhibitor that is now in clinical trials.

Currently, Dr. Stein heads the *Laboratory for Drug Discovery in Neurodegeneration*. The LDDN originated as part of the Partner's Program in Neurodegenerative Diseases which includes scientists at the Center for Neurologic Diseases of the Brigham and Women's Hospital and the Center for Aging, Genetics and Neurodegeneration (CAGn) at the Massachusetts General Hospital. In 2001, the LDDN was formally established as one of the five core groups of the Harvard Center for Neurodegeneration and Repair. The mission of the LDDN is to discover new chemical agents that can be used as: (i) probes of cellular mechanisms of disease and (ii) lead structures for the development of new therapeutics. To discover these compounds, we will screen large collections of drug-like molecules as well as a smaller library of FDA-approved drugs for their ability to modulate the biological activity of molecular and cellular processes that are thought to have causative roles in neurodegenerative diseases. Optimization of these compounds to enhance therapeutically-relevant properties will be achieved by focused programs of medicinal chemistry.

LTC Karl Friedl

Research Area Director

Military Operational Medicine (MOM) Research Program

U.S. Army Medical Research and Materiel Command

Fort Detrick, Frederick, Maryland

Karl E. Friedl, Ph.D., is the Research Area Director for the Military Operational Medicine (MOM) Research Program at the U.S. Army Medical Research and Materiel Command in Frederick, Maryland. The MOM program includes research conducted at three intramural laboratories, three detachments, and through multiple extramural grants and contracts in three interrelated areas: bioenergetics and environmental medicine, systems hazards and injury sciences, and neuropsychological and performance research. This program also includes management of the DoD Gulf War Illnesses research portfolio and several Congressional special interest programs such as bone health research, neurotoxin exposure treatment (Parkinson's) research, and nutrition research. Prior to this assignment, Lieutenant Colonel Friedl conducted research in the Occupational Physiology Division of the U.S. Army Research Institute of Environmental Medicine in Natick, Massachusetts, where he specialized in physiological limits of prolonged, intensive military training. Previously, he worked in the Department of Clinical Investigation at Madigan Army Medical Center in Tacoma, Washington, performing studies in endocrine physiology. He received his Ph.D. in physiology in 1984 from the Institute of Environmental Stress at the University of California, Santa Barbara. He has published original articles on diverse physiological investigations such as: functional consequences of semi-starvation in high intensity field training; body composition estimation methods and standards for DoD fitness regulations; health and performance changes in female Army recruit training; atropine and oxime interactions in nerve agent antidote delivery systems; steroid regulation of spermatogenesis for potential male contraception; and noninvasive physiological measurement systems to monitor hemorrhage and resuscitation.

CURRICULUM VITA

CINDY PATRICIA LAWLER

PERSONAL INFORMATION

Work Address: National Institute of Environmental Health Sciences
79 Alexander Drive, Bldg 4401
Research Triangle Park, NC 27709
Telephone: (919) 316-4671 (office)

EDUCATION:

B.A.	1981	Univ. of North Carolina, Charlotte	Psychology
M.A.	1983	Northeastern Univ., Boston	Experimental Psychology
Ph.D.	1987	Northeastern Univ., Boston	Experimental Psychology
Post-doctoral	1987-91	Univ. of North Carolina, Chapel Hill	Neuropharmacology

EMPLOYMENT HISTORY:

1981-1983: Teaching Assistant, Department of Psychology, Northeastern University, Boston, MA
1983-1987: Instructor, Department of Psychology, Northeastern University, Boston, MA
1987-1990: Interdisciplinary post-doctoral fellow (Supervisor, Dr. Mark H. Lewis), Brain and Development Research Center, University of North Carolina, Chapel Hill, NC
1990-1991: Morris Lipton Fellow, Brain and Development Research Center, University of North Carolina, Chapel Hill, NC
1992-2000: Research Assistant Professor, Curriculum in Toxicology and Department of Psychiatry, and Research Scientist, Brain and Development Research Center, University of North Carolina, Chapel Hill, NC
1996-2000: Adjunct Assistant Professor, Department of Biostatistics, School of Public Health, University of North Carolina, Chapel Hill, NC
2000-present: Scientific Program Administrator, Organ and Systems Toxicology Branch, Division of Extramural Research and Training, National Institute of Environmental Health Sciences

PROFESSIONAL SERVICE:

appointed for four-year term, NIMH Small Business Innovative Research Review Committee, 1995-1999
ad hoc reviewer for American Institute for Biological Sciences, Neurotoxicology Review group, 1998.

EDITORIAL ACTIVITIES:

ad hoc reviewer for the following journals:

Behavioral Neuroscience
Fundamental and Applied Toxicology
Neurotoxicology and Teratology
Physiology and Behavior
European Journal of Pharmacology

PROFESSIONAL MEMBERSHIPS:

American Institute for Biological Sciences
Society for Neuroscience
Phi Kappa Phi

Dr. Diane Murphy

Program Director, Neurodegeneration Group, National Institute of Neurological Disorders and Stroke (NINDS).

Dr. Diane Murphy is a Program Director in the Neurodegeneration Group. Her portfolio consists of the basic science of Alzheimer's and Parkinson's disease. She received her Ph.D. in biology, with an emphasis on imaging, including light, fluorescence, and electron microscopy. She then received a fellowship to work in the NINDS intramural program, where she studied the cell biology and morphological plasticity of primary hippocampal neurons in the laboratory of neurobiology with Dr. Tom Reese. She then worked in an Alzheimer's Disease Center, headed by Drs. John Trojanowski and Virginia Lee, at the University of Pennsylvania. There she focused on cellular and molecular studies of alpha synuclein and presenilin.

Dr. Murphy is particularly interested in the cell biology of neurodegenerative diseases. Specifically she is interested in how synaptic loss contributes to cell death and degeneration, and how the discovery of mutated proteins and understanding their normal and abnormal neuronal functions give insight into the disease process.

Dr. Linda S. Sigmund
GlaxoSmithKline

Linda S. Sigmund, M.D., is a nationally recognized neurologist specializing in Parkinson's Disease. Her current practice includes more than 700 patients with Parkinson's and related disorders. She participates in clinical research in the pharmacological treatment of Parkinson's and recently began the use of deep brain stimulation surgery.

Dr. Sigmund established the first Parkinson's support and exercise program in the Washington, D.C. metropolitan area in 1986. She is presently the Medical Director of the Capital Chapter of the National Parkinson Foundation, overseeing the operation of more than 20 support groups and 3 exercise programs that serve 5,000 patients. Washingtonian magazine named Dr. Sigmund one of the "Top Doctors" among thousands in the greater Washington-Baltimore area in a poll that surveyed physicians.

Dr. Sigmund holds a B.S. degree from the University of Bridgeport, a post-graduate degree in physical therapy from the University of Pennsylvania, and a M.D. from the Georgetown School of Medicine. A recipient of Uniformed Services Health Scholarship, she completed her residency in neurology at Letterman Army Hospital and the University of California, San Francisco. Dr. Sigmund served in the U.S. Army as a neurologist at Ft. Bragg and Chief of Neurology at Ft. Belvoir, where she received a Meritorious Service Medal.

**Joseph R. Bianchine, M.D.,PH.D.,
F.A.C.P., F.A.C.C.P.**

Senior Scientific Advisor

Joseph Bianchine serves as Senior Scientific Advisor to SCHWARZ PHARMA. He is a Fellow of the American College of Physicians and the American College of Clinical Pharmacology. He is a Diplomat of the American Board of Clinical Pharmacology. He is a member of several scientific societies and national committees and served as President of the American Society of Clinical Pharmacology and Therapeutics.

After completing a doctorate in pharmacology, he completed his medical training in Internal Medicine at the Johns Hopkins University College of Medicine in Baltimore. In 1983, after serving as Professor and Chairman of the Department of Pharmacology and Director of Clinical Pharmacology at Ohio State University College of Medicine for ten years, he began his career in the pharmaceutical industry as Vice President for Medical Research at Hoffman LaRoche, and then at similar positions with Dupont and with Farmitalia-Carlo Erba. A series of mergers led to his recent position of Senior Vice President at Pharmacia and Upjohn where he served on the worldwide Corporate Development Board with Lars Ekman.

He has authored more than 300 scientific articles and abstracts, 30 books and book chapters, all in the broad area of clinical pharmacology and therapeutics. **He has extensive research experience in the drug management of Parkinson's disease and other neurologic diseases.** 15 NDAs have been approved under his directorship in the Industry.

David J. Brooks MD DSc FRCP Fmed Sci

AMERSHAM HEALTH

David Brooks is Hartnett Professor of Neurology and Head of the Department of Sensorimotor Systems in the Faculty of Medicine, Imperial College, London. He also is Head of the Neurology Group at the Medical Research Council Clinical Sciences Centre, Hammersmith Hospital, London. He is Chief Medical Officer of Imanet and Clinical Director of Imaging Research Solutions Ltd., a subsidiary of Amersham Health PLC.

He is Chairman of the Scientific Issues Committee of the Movement Disorder Society, a member of the International Research Advisory Board of the Michael J. Fox Foundation for Parkinson's Research, a member of the Medical Advisory Panel of the UK Parkinson's Disease Society (Chairman, 1996-7) and UK Huntington's Disease Association. He was Chairman of the Council of Management of the UK Parkinson's Disease Society 1997-8. He is on the Editorial Boards of the Journal of Neurology, Neurosurgery, and Psychiatry, the Journal of Neural Transmission, and Synapse and was on the editorial board of Movement Disorders 1994-1998.

His research involves the use of positron emission tomography to study the efficacy of putative neuroprotective and restorative agents in Parkinson's Disease and performance of therapeutic trials. To date he has published over 200 reports in peer reviewed journals and his research currently is supported by grants from the Medical Research Council, Wellcome Trust, UK Parkinson's Disease Society, Action Research, and industry.

Roy A. E. Bakay, M.D.

Titan Pharmaceuticals

Dr. Roy A. E. Bakay is director of functional and restorative neurosurgery at the Chicago Institute of Neurosurgery and Neuroresearch (CINN) as well as professor and vice chairman of neurological surgery at Rush Medical College, Rush-Presbyterian-St. Luke's Medical Center.

A board-certified neurosurgeon who has been named in the publication, "Best Doctors in America" since 1994, Dr. Bakay is highly regarded for his care of patients with movement disorders. He specializes in the surgical treatments of Parkinson's disease, essential tremor, dystonia and other movement conditions. Dr. Bakay is a leading authority in pallidotomy. He was instrumental in developing microelectrode mapping of the pallidus.

The recipient of numerous honors and awards, Dr. Bakay has received international recognition for his work as a physician, author, educator and research scientist. The National Institutes of Health and other prestigious organizations have funded his studies on pallidotomy, deep brain stimulation, neural tissue transplantation, and gene therapy techniques.

Dr. Bakay earned his medical degree from Northwestern University Medical School in 1975. Six years later, he completed his residency training in neurological surgery at the University of Washington School of Medicine in Seattle. Following his residency, Dr. Bakay held a fellowship in neuronal plasticity at the National Institutes of Health.

In 1982, Dr. Bakay embarked on a long and distinguished career at Emory University School of Medicine in Atlanta, Georgia, where he served as vice-chairman of the Department of Neurological Surgery from 1995 until he joined CINN in 2000.

Dr. Bakay is a member of many professional organizations. He has served as president of the Joint Section on Stereotactic and Functional Neurosurgery of the American Association of Neurological Surgeons and the Congress of Neurological Surgeons. He is currently president of the American Society for Neural Transplantation and serves on the executive board of the American Society of Stereotactic and Functional Neurosurgery.

Phyllis M. Salzman, PhD
Director, CNS Projects
Teva Neuroscience, Inc.
North Wales, PA

Phyllis Salzman, PhD joined Teva Neuroscience, Inc. in January, 2000. She is Director, CNS Projects where she is responsible for the North American clinical development of two novel therapeutic agents for the treatment of Parkinson's disease and other neurodegenerative disorders. Teva Neuroscience, Inc., a division of Teva Pharmaceutical Industries, Ltd., is dedicated to the investigation and development of innovative products and services in neurology. Teva Pharmaceutical Industries, Ltd., headquartered in Israel, is among the largest generic pharmaceutical companies in the world.

Dr. Salzman has over 20 years' experience in pharmaceutical drug development. Her clinical development experience extends from Phases I through IV and across therapeutic areas ranging from gastroenterology and hematology to surgery, urology and neurology. She has developed biologics as well as conventional drugs and conducted trials in adult and pediatric populations. Dr. Salzman is proudest to have contributed to the availability of drugs for orphan diseases. She earned her doctorate in pharmacology at Yale University and is a founding member and past-president of the Philadelphia chapter of the Association for Women in Science.

Updated April, 2002.



Titan Pharmaceuticals, Inc.

Company:
Alison Roselli
Director, Corporate Communications
650-244-4993

Media:
Rebecca Novak
GCI Group
212-537-8116

Investors:
Robert Ferris
GCI Group
212-537-8025

EMBARGOED UNTIL 2:45PM MT (4:45PM ET), WEDNESDAY, APRIL 17, 2002

**TITAN ANNOUNCES POSITIVE LONG-TERM RESULTS OF PHASE I/II STUDY
OF SPHERAMINE® IN PARKINSON'S DISEASE**

*Data Presented at American Academy of Neurology Demonstrate Significant Improvement
in Motor Function in Late-Stage Parkinson's Patients*

South San Francisco, CA – April 18, 2002 – Titan Pharmaceuticals, Inc. (ASE:TTP) today announced that treatment with Spheramine® produced a nearly 50 percent improvement in motor function in patients with advanced Parkinson's disease in a recently completed, 12 month Phase I/II study. Spheramine is a novel cell therapy product for the treatment of Parkinson's disease being developed by Titan in collaboration with Schering AG (FSE:SCH, NYSE: SHR), Titan's corporate partner for the development of Spheramine.

The new data, presented today at the 54th annual meeting of the American Academy of Neurology, also demonstrated significant improvement in quality of life for all patients treated, with no significant adverse events. Based upon the positive results of this study, Titan and Schering are preparing to initiate a randomized clinical study of Spheramine.

"The long-term results from this pilot clinical study with Spheramine are very favorable and confirm the preliminary findings of the study," said Ray L. Watts, M.D., professor and vice chairman of the Department of Neurology at Emory University School of Medicine and principal investigator of the study. "These data indicate that this new approach may hold significant promise for improved treatment of Parkinson's patients."

Positive Efficacy and Safety Results Seen

The open label Phase I/II study in six patients with advanced PD was designed to evaluate the safety of Spheramine and its efficacy in improving motor function. Patients were evaluated pre- and post-treatment, both 'on' and 'off' their normal medication, using the Unified Parkinson's Disease Rating Scale (UPDRS), a standard measure of Parkinson's disease severity. The primary efficacy endpoint was the 'off' state motor

score of the UPDRS at 12 months, which was evaluated pre-treatment and every three months thereafter.

All patients demonstrated significant improvement in motor function, and other outcome measures, with no safety concerns. At 12 months post treatment:

- Patients experienced an average 48 percent improvement in motor UPDRS score, off all other medication.
- Patients experienced an average 43 percent improvement in total UPDRS score.
- Improvements were noted in quality of life and activities of daily living.
- Half the patients demonstrated a reduction in pre-existing dyskinesias (involuntary movements) while the remainder had no change from baseline.
- No 'off' state dyskinesias were observed (patients off PD medication overnight).
- All six patients completed the one-year study, with no safety concerns.

Patients will continue to be monitored beyond the one-year study.

"We are very pleased with the success of this pilot study and look forward to advancing the Spheramine development program into randomized, clinical testing in the near future," said Dr. Joachim-Friedrich Kapp, head of the Strategic Business Unit Specialized Therapeutics of Schering AG.

Spheramine and Parkinson's Disease

In Parkinson's disease, a neurotransmitter called dopamine is deficient in certain brain regions causing progressive motor symptoms such as tremors, rigidity, and slowed, difficult movements of the arms and legs. Spheramine consists of normal human cells that provide dopamine (RPE cells) attached to microcarriers, and is designed to deliver dopamine to the regions of the brain affected by Parkinson's disease. In this study, Spheramine was delivered unilaterally to the brain. Subsequent studies of Spheramine will utilize bilateral treatment, which may further enhance the therapeutic profile.

"The positive clinical study results demonstrate the potential of Spheramine to contribute significantly to the treatment of Parkinson's patients and we look forward to further clinical testing," said Louis R. Bucalo, M.D., chairman, president and CEO of Titan. "In addition, these data further support the broad potential value of Titan's CCM technology on which Spheramine is based."

Clinical Results Driven by Broadly Enabling Technology

Spheramine utilizes Titan's breakthrough cell-coated microcarrier (CCM™) technology, which allows normal human cells to survive after surgical injection into the brain. Cell therapy for the treatment of central nervous system (CNS) disorders is normally limited by death of most of the transplanted cells after a few weeks. By maintaining their viability and function, Titan's innovative technology allows the use of normal mature cells, rather than embryonic or stem cells, and eliminates the need for drugs to suppress rejection of the cells. This breakthrough technology potentially allows any cell type to be used in neural transplantation, moving the science of CNS cell therapy beyond stem cells to numerous other cell types.

Numerous scientific studies have demonstrated the efficacy of Titan's CCM technology, which allows normal cells to survive implantation to the brain and provide therapeutic activity. Separately reported, controlled studies in animal models of Parkinson's disease and glioma, have confirmed the therapeutic potential of this platform technology. Additional controlled, preclinical efficacy studies will be presented at the International Society for Cellular Therapy in May.

About Titan

Titan Pharmaceuticals, Inc. (ASE:TTP) is a biopharmaceutical company focused on the development and commercialization of novel treatments for central nervous system (CNS) disorders, cancer and other serious and life-threatening diseases. Titan has assembled a deep pipeline of products utilizing novel technologies that have the potential to significantly improve the treatment of these diseases. Titan also establishes important partnerships with multinational pharmaceutical companies and government institutions for the development of its products.

The press release may contain "forward-looking statements" within the meaning of Section 27A of the Securities Act of 1933 and Section 21E of the Securities Exchange Act of 1934. Such statements include, but are not limited to, any statements relating to the Company's development program and any other statements that are not historical facts. Such statements involve risks and uncertainties, including, but not limited to, those risks and uncertainties relating to difficulties or delays in development, testing, regulatory approval, production and marketing of the Company's drug candidates, unexpected adverse side effects or inadequate therapeutic efficacy of the Company's drug candidates that could slow or prevent product development or commercialization, the uncertainty of patent protection for the Company's intellectual property or trade secrets and the Company's ability to obtain additional financing if necessary. Such statements are based on management's current expectations, but actual results may differ materially due to various factors, including those risks and uncertainties mentioned or referred to in this press release.

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TEVA Neuroscience, Inc.
Presentation summary – current work in Parkinson's Disease
Phyllis Salzman, PhD

Rasagiline mesylate is a novel, selective and potent irreversible monoamine oxidase type B (MAO-B) inhibitor for the treatment of Parkinson's Disease (PD), that can be used alone or in combination with levodopa. Teva has successfully completed two phase II studies in the US, Israel and Hungary and is currently conducting two large phase III trials in North America, Europe, South America and Israel. In a completed 6-month North American trial of 400 newly diagnosed PD patients, rasagiline at 1 mg and 2 mg per day showed a beneficial effect on PD symptoms, compared to placebo. Rasagiline treatment was then extended for another 6 months. Patients who received rasagiline for 12 months had a slower decline in their PD than did patients who received rasagiline for only 6 months. The results suggest that rasagiline has a beneficial effect on PD symptoms, and may also slow the rate of disease progression.

Etilevodopa (EtiLD), the ethyl ester of levodopa, is converted to levodopa in the stomach and small intestine. EtiLD is taken throughout the day instead of standard levodopa. Unlike levodopa, EtiLD dissolves readily in water, which should result in better, faster and more reliable absorption of levodopa. For patients with longstanding PD who have fluctuating responses to levodopa, EtiLD is expected to shorten the "Time to ON" and reduce the frequency of dose failures or "No ON" episodes. Teva has successfully completed a phase II study in Israel, and phase III studies in North America and Europe are ongoing.

Senator Paul Wellstone

(D-MN)

U.S. Senator Paul Wellstone, the senior senator from Minnesota, was born to Leon and Minnie Wellstone on July 21, 1944. In 1963 he married Sheila Ison with whom he has three children, David, Marcia, and Mark; the Wellstones have six grandchildren, Cari, Keith, Joshua, Acacia, Sydney, and Matt.

Paul grew up in Arlington, VA and attended Wakefield and Yorktown high schools. He then went on to the University of North Carolina in Chapel Hill where he was a champion wrestler. In 1965, he graduated with a B.A. in Political Science and earned a Ph.D. in Political Science in 1969. He accepted a teaching position at Carleton College in Northfield, MN and taught there for 21 years before being elected to the U.S. Senate.

In 1990, underdog Paul Wellstone rallied together a dedicated volunteer force and traversed the state in his trademark Green Bus to become the only Senate contender to unseat an incumbent. In 1996, Paul Wellstone promised Minnesotans that he would run a grassroots campaign that would make them proud. He mobilized his volunteers and field organization to generate a massive participation in the political process, now a model for the nation.

United States Senator

Paul Wellstone's experience as a teacher and grassroots organizer in Minnesota provides the framework for his progressive policies and priorities as a Senator. Minnesotans have a proud tradition of electing people like Hubert Humphrey, Eugene McCarthy and Walter Mondale--U.S. Senators--who through their commitment and hard work became strong voices and real fighters for those who had no one else to fight for them. Paul Wellstone takes great pride in being a part of this Minnesota tradition.

During his first Senate term he helped lead the fight to ensure that people would be able to take time off from work to care for a sick child or aging parent without losing their jobs, and to ensure that health care is accessible and affordable for all Minnesotans. He led the successful fight to raise the federal minimum wage, and he supported legislation that would protect the security of thousands of Minnesotans and their families by preventing corporations from raiding seniors' pension funds. And, he authored historic new lobbying disclosure and ethics reforms which have

changed the way business is done in Washington. During his second term, Paul Wellstone has worked to focus our nation's attention on children, our most important national resource, and continues to be an outspoken national leader in the fight for economic justice for all. As a Senator for Minnesota, Paul Wellstone continues to fight for a progressive, values-based working families agenda and for major political reforms designed to transform the way federal campaigns are financed and organized.

CURRICULUM VITAE

Jeffrey H. Kordower, Ph.D.

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Date of Birth: 8/18/58

Place: New York City

Status: Married to Lynn T. Kordower

Children: Andrew Jason, 10/18/85
Adam Michael, 02/12/88

SS#: 053-46-0252

EDUCATION

B.A.	Queens College C.U.N.Y., New York City (Psychology/Sociology)	1980
M.A.	Queens College C.U.N.Y., New York City (Psychology)	1983
Ph.D.	Queens College C.U.N.Y., New York City (Neuropsychology)	1984
Postdoc	University of Rochester School of Medicine, Rochester, New York (Neurobiology and Anatomy)	1984- 1986

Thesis: "Vasopressin Analgesia: Specificity of Action and Non-Opioid Effects"

Thesis Advisor: Richard J. Bodnar, Ph.D.

Postdoctoral Advisor: Don M. Gash, Ph.D.

HONORS

1980	Award for Excellence in Research in Psychology, Queens College
1983	Elected full member, Sigma Xi National Research Honors Society
1985-87	John Douglas French Fellow for the Study of Alzheimer's Disease
1994-02	International Scientific Organizing Committee, International Symposia on Neural Transplantation
1995	Hassel Foundation Keynote Lecturer
1996	President, American Society for Neural Transplantation
1998-	Huntington's Disease Society of America; National Speakers Bureau
1999-	Keynote Speaker, Northern Northeastern Neurological Society
2000	Keynote Speaker, Central Michigan University, Brain Awareness Week
2001	Bernard Sanberg Memorial Award for Brain Repair
2001	Keynote Lecture, Rocky Mountain Movement Disorder Society

Dr. Deborah Cory-Slechta
University of Rochester

Dr. Deborah Cory-Slechta attended Western Michigan University where she received both a B.A. degree in 1971 and an M.A. degree in 1972. She subsequently earned a Ph.D. degree from the University of Minnesota in 1977 in a combined Pharmacology/Psychology training program devoted to drug abuse and addiction. After serving as a Jr. Staff Fellow of the National Center for Toxicological Research, she began postdoctoral work at the University of Rochester in the Division of Toxicology of the Department of Radiation Biology and Biophysics. She was appointed Assistant Professor in 1984 and became a member of the Department of Environmental Medicine in its inception in 1992. She rose to the level of Professor in 1997 when she also became acting Chair of Neurobiology and Anatomy. In 1998, she returned to the Department of Environmental Medicine as Chair and as Director of its NIEHS Environmental Health Sciences Center which was renewed under her leadership during that year. In 2000, she was appointed as the first Dean for Research and Director of the Aab Biomedical Institute at the University of Rochester Medical School.

Her research career has focused on the area of behavioral and neurotoxicology, particularly as it relates to the neurochemical mechanisms underlying the cognitive and attention impairments produced by chronic low level lead exposure. More recently her laboratory has begun work on the role of environmental pesticides as risk factors for Parkinson's disease and how they interact with age, genetic background, and other environmental exposures. These research efforts have resulted in over 85 papers and book chapters to date. She has served on the National Institute of Environmental Health Sciences Advisory Council and as a member of the Committee on Toxicology of the National Academy of Sciences. She has been appointed to numerous advisory committees for NIH, EPA, ATSDR, FDA and the U.S. Department of Defense on issues of neurotoxicology. She has held the elected position of President of the Neurotoxicology Specialty Section of the Society of Toxicology and as President of the Behavioral Toxicology Society and is also a Fellow of the American Psychological Association. In addition, she has served as Associate Editor for the journals Neurotoxicology, Toxicology, Fundamental and Applied Toxicology, and Toxicological Sciences and on the Editorial Board of Toxicology and Applied Pharmacology.

John D. Gearhart, Ph.D.
C. Michael Armstrong Professor
Johns Hopkins Medicine

Professor of Gynecology and Obstetrics, Professor of Physiology, Professor of Comparative Medicine,
The Johns Hopkins University School of Medicine
Professor of Biochemistry and Molecular Biology, The Johns Hopkins University Bloomberg School of
Public Health
Director, Developmental Genetics Division, Gynecology and Obstetrics
Director of Research, Gynecology and Obstetrics

EDUCATION

Cornell Univ., Ithaca NY	Ph.D. 1970	Major: Genetics, Development & Embryology
Univ. New Hampshire, Durham NH	M. Sc. 1966	Major: Genetics
Pennsylvania State Univ., Univ. Park PA	B. Sc. 1964	Major: BioSci

PUBLICATIONS (Selected of 229: transgenesis, Down Syndrome, stem cells)

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RESTAURANTS ON CAPITOL HILL

2 Quail- American, 320 Massachusetts Ave NE, 543-8030
Armand's Chicago Pizzeria, Italian, 226 Massachusetts Ave NE, 547-6600
Barolo, Italian, 223 Pennsylvania Ave SE, 547-5011
Bis, French-American, 15 E St NW, 824-9900
Bull Feathers, American, 410 1st St SE, 543-5005
Burrito Brothers, Southwestern, 205 Pennsylvania Ave, SE, 543-6835
Cabernet Café, Mediterranean, 320 D St NE, 543-2708
Café Berlin, American, German, 322 Massachusetts Ave NE, 543-7656
Capitol City Brewing Company, American, 2 Massachusetts Ave NE, 842-2337
Capitol Lounge, Cigar Lounge, Martini Lounge, 229 Pennsylvania Ave SE, 547-2098
Capitol View Club, American, 400 New Jersey Ave, NW, 783-2582
Dubliner, Irish, 520 N. Capitol St NW, 737-3773
Hawk 'n' Dove, Irish, American, 329 Pennsylvania Ave SE, 543-3300
Hunan on Capitol Hill, Chinese, 201 D St NE, 544-0102
Il Radicchio, Italian, 223 Pennsylvania Ave SE, 547-5114
Kelly's Irish Times Pub, American-Irish Pub, 14 F St N, 543-5433
La Brasserie, French, 239 Massachusetts Ave NE, 546-9154
La Colline, French, 400 N. Capitol St NW, 737-0700
The Monocle, American, 107 D St NE, 546-4488
My Brother's Place, American-Bar, PM only, 130 C St NW, 347-1350
Red River Grill, Southwestern, 201 Massachusetts Ave NE, 546-7200
Senators, Holiday Inn on the Hill, 415 New Jersey Ave NW, 347-7678
The Sunspot Café, American-Mediterranean, 440 1st St NW, 783-8331
Tavern on the Hill, American, 233 2nd St NW, 639-0441
Taverna- The Greek Islands, Greek, 307 Pennsylvania Ave SE, 547-8360
Thai Roma, Thai, 313 Pennsylvania Ave SE, 544-2338
Tortilla Coast, Southwestern, Tex-Mex, 400 1st St SE, 546-6768
White Tiger, Indian, 301 Massachusetts Ave NE, 546-5900
Yamato, Japanese, Shushi, 201 Massachusetts Ave NE, 546-3424

Union Station 50 Massachusetts St. NE, 371-9441:

Cafes:

Au Bon Pain, 898-0299
Corner Bakery Café, 371-8811
Johnny Rockets, 289-6969
McDonald's, 408-5014
Sbarro-The Italian Eatery, 289-0767

Restaurants:

America, American, 682-9555
B. Smith's, Southern, 289-6188
Center Café, Continental, 682-0173

Union Station Continued:

Restaurants:

East Street Café, Chinese, 371-6188
Pizzeria Uno, Italian, 842-0438
Station Grill, 898-4745
Thunder Grill, Tex-Mex, 898-0051

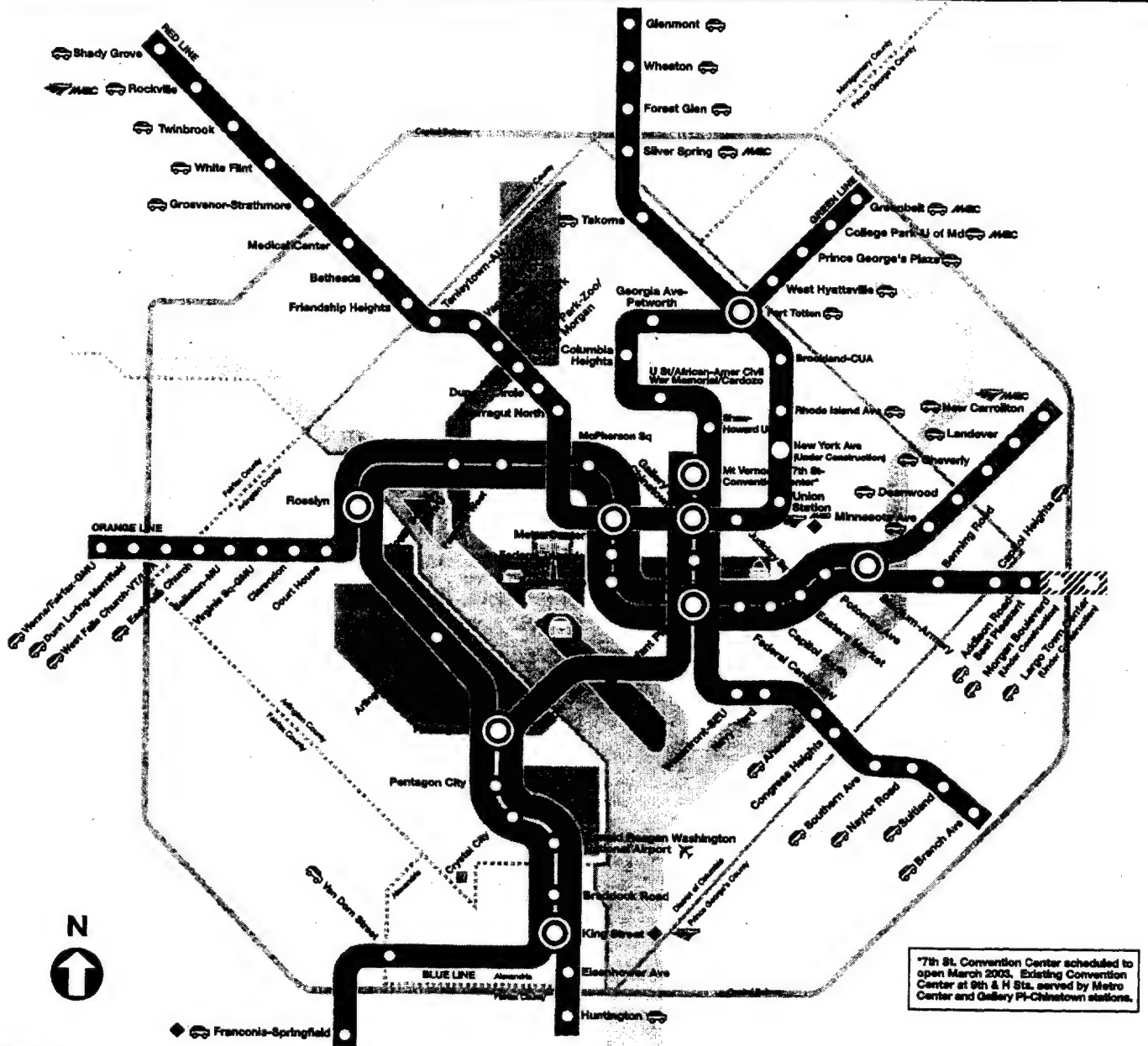
Casual Dining/Food Court:

Acropolis 785-7333
Auntie Anne's Pretzels 289-9883
Bagel Works, 289-9883
Boardwalk Fries, 371-2860
Bain's Deli, 682-1910
Buck's County Coffee, 682-1326
Burrito Brothers, 289-3652
Cajun Grill, 842-0028
Calypso Kitchen, 408-0744
Cookie Café, 682-3060
Flamer's Charburgers, Inc., 371-8253
Frank & Stein-Dogs & Drafts, 289-3661
Georgetown Seafood & Grill, 842-2344
Gourmet Corner, 898-2010
The Great Steak & Fry Co., 371-9830
Haagen Dazs, 789-0953
Ichiban Teriyaki & Tempura, 789-8342
Indian Delight, 842-1040
Kabuki Sushi, 789-1159
Larry's Cookies, 289-7586
Mama Ilardo's Pizzeria, 371-9072
Mamma But Donuts, 408-9464
Panda's Rice Bowl, 789-0382
Paradise Smoothies, 289-9560
Pasta T' Go Go, 289-4720
Pik-A-Pita, 842-2438
Primo Cappuccino, 898-0292
Salad Works, 898-0550
Soup Nutsy, 216-0160
Sweet Factory, 371-8660
Vaccaro's, 371-2855
Wingmaster's Grill, 371-9614

M System Map

Legend

- Red Line • Glenmont to Shady Grove
- Orange Line • New Carrollton to Vienna/Fairfax-GMU
- Blue Line • Franconia-Springfield to Largo Town Center
- Green Line • Branch Avenue to Greenbelt
- Yellow Line • Huntington to Mt Vernon Sq/7th St-Convention Center



*7th St. Convention Center scheduled to open March 2003. Existing Convention Center at 9th & H Sts. served by Metro Center and Gallery Pl-Chinatown stations.

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- No Smoking
- No Eating or Drinking
- No Animals (except service animals)
- No Audio or Video Devices (without earphones)
- No Litter or Spitting
- No Dangerous or Flammable Items

What to do while in Washington, DC:

Memorials, Monuments and Points of Interest

- The Corcoran Gallery of Art Museum - 17th Street and New York Avenue, NW - one block west and south of the White House. The main entrance is on 17th Street. Special needs access is at 1701 E Street, around the corner from the 17th Street entrance. 10:00 a.m. to 5:00 p.m. every day except Tuesdays; extended hours Thursday evenings until 9:00 p.m., except Thanksgiving. The museum is closed Tuesdays, Christmas Day and New Year's Day. Suggested contributions for admission to the Corcoran are \$3 - \$6 for adults, \$1 - \$4 for senior citizens and students, and \$5 - 10 for family groups. Phone: (202) 639-1700 Metro Stop: Four blocks from the Farragut West station or Farragut North station.
- Ford's Theatre & Lincoln Museum - 511 10th Street, NW - 10th Street Between E & F Streets. Building is open every day from 9:00am to 5:00pm with the exception of Christmas. Telephone: (202) 426-6924. Metro Stop: the closest station to the theatre is Metro Center
- The Hall of States Building - 444 North Capitol Street, NW. This building houses 32 state offices. For information call the Council of State Governments at (202) 624-5386.
- The United States Holocaust Memorial Museum - The Museum is located just south of Independence Ave., SW. between 14th Street and Raoul Wallenberg Place (formerly 15th St.). It is open daily 10 am to 5:30 pm and closed on Yom Kippur and Christmas Day. From April 1 through September 2, 1999, the Museum will also be open until 8pm on Thursdays. There is an entrance also on 14th street, next to the Bureau of Printing & Engraving. Permanent exhibition is recommended for ages 11 and up. Daniel's Story is recommended for ages 8 and up. The visit will take from an 1 1/2 to 3 hours. ONLY the Permanent Exhibition requires a timed entry pass to begin the self-guided tour of the Museum's primary exhibition. Passes are FREE and are NOT required for the Museum's other exhibitions, memorials, resources and facilities. Metro Stop: Smithsonian on the blue or orange lines exit at 12th and Independence Avenue. Telephone: (202) 488-0400.
- The Thomas Jefferson Memorial - South bank of the Tidal Basin-The memorials and monuments on the National Mall are opened daily from 8:00 AM until 11:45 PM, every day except Christmas Day. There are no fees to visit any of the monuments or memorials on the National Mall. At the Swan Boathouse you can rent a paddle boat to cruise on the Basin. The Smithsonian Metro stop comes out on the National Mall. Phone: (202) 426-6841
- Korean War Veterans Memorial - The memorial is staffed from 8 a.m. to midnight every day except December 25 by park rangers who are available to answer questions and present interpretive themes. A bookstore in the nearby Lincoln Memorial sells informational items relating to both the memorial and the Korean War. The Korean War Veterans Memorial is part of the National Park System, one of more than 360 parks representing our nation's natural and cultural heritage. Address inquiries to: Superintendent, National Capital Parks-Central, 900 Ohio Drive SW, Washington, DC 20242.
- The Lincoln Memorial - West Potomac Park at the foot of 23rd Street, NW. The memorials and monuments on the National Mall are opened daily from 8:00 AM until 11:45 PM, every day except Christmas Day. Telephone: (202) 426-6895. Metro Stop: Foggy Bottom or the Smithsonian Metro stop which comes out on the National Mall.

- The Washington Dolls' House and Toy Museum - 5236 44th Street, NW. Antique dolls' houses, dolls, toys and games. Adults, \$4. Seniors, \$3. Children, \$2. Metro Stop: Take the Red Line train to Friendship Heights. From the Jenifer Street exit, turn left on Wisconsin Avenue, and walk half a block to Jenifer. Turn left on Jenifer Street and walk half a block to 44th Street. Turn left on 44th. The Museum in the middle of the block, on your right. Telephone: (202) 244-0024 or or 202-363-6400.
- The Washington Monument - On the Mall at 15th Street, SW. Open 9 a.m. until 5:00 p.m. Tickets are required. They are free and available at the booth located on the west side of 15th Street, NW, on the Mall. Advance Tickets (small fee charged): Ticketmaster: (DC Metro) 202-432-7328 (Outside DC) 1-800-551-7328. Facilities: Bookstore, Restrooms, Museum. Information: 202-426-6841. Metro stop: Smithsonian

Outdoor Theaters

- Merriweather Post Pavilion - 10475 Little Patuxent Parkway. Located in Columbia, Maryland between Baltimore and Washington D.C. and is readily accessible from I-95. Performing arts center offers symphonic music, and pop concerts. Ticket Infor.: 703-218-6500 in Washington D.C.; 410-481-6500 in Baltimore; 800-955-5566 elsewhere
- Wolf Trap Farm Park for the Performing Arts - 1551 Trap Road Vienna, VA 22182. The nation's first National Park for the performing arts offers opera, symphonic music, pop concerts, jazz and ballet. Only open during warm weather. Price of admission varies depending on program. Telephone: 703-255-1800.

Plantations and Historic Mansions

- The Dumbarton Oaks - 1703 32nd Street, NW (one block east of Wisconsin Avenue between R and S Streets in Georgetown). Gardens open daily. April-October: 2-6 pm, \$4.00 admission; children and senior citizens \$3.00. November-March: 2-5 pm, free admission. Closed during inclement weather, national holidays, and Christmas eve. Museum open Tuesday through Sunday from 2:00pm to 5:00pm. Free admission but donations are accepted. Closed for national holidays. Telephone: (202) 339-6401.
- Mount Vernon Estate and Gardens - Home of George Washington. Mount Vernon is open seven days a week, every day of the year, including holidays and Christmas.
Schedule:
 - April through August from 8:00 a.m. - 5:00 p.m.
 - March, September, October from 9:00 a.m. - 5:00 p.m.
 - November through February from 9:00 a.m. - 4:00 p.m.

General Admission

- Adults - \$ 8.00
- Senior Citizens, age 62 and above (with identification) - \$7.50
- Children age 6 through 11 (accompanied by an adult) - \$4.00
- Children age 5 and under FREE (accompanied by an adult)
- Annual Pass (unlimited admission for one year) - \$14.00

FedExField
1600 Raljon Road
Raljon, MD 20785-4236

- Washington Wizards - MCI Center: 601 F Street NW Washington, DC 20004 (Between 6th and 7th, and F and G Street)
For season tickets and partial plans call (202) 661-5050.
For single-game tickets, call TicketMaster at (202) 432-SEAT.

Theaters

- Arena Stage - 6th and Maine Ave, SW. Telephone: (202) 488-3300 or (800) 777-2238.
- Capitol Steps - The Capitol Steps now perform every Friday & Saturday night at 7:30 pm at the Ronald Reagan Building and International Trade Center (1300 Pennsylvania Avenue, NW Washington, DC). Tickets are \$31.50 and can be purchased by calling Ticketmaster at 202-432-7328 or by going to www.ticketmaster.com.
- Discovery Theater - Smithsonian's Arts and Industries Building 900 Jefferson Drive, SW. Performances for young audiences Telephone: (202) 357-1500.
- Ford's Theatre & Lincoln Museum - 511 10th Street, NW. Telephone: (202) 638-2941.
- John F. Kennedy Center for the Performing Arts - New Hampshire Avenue at Rock Creek Parkway, NW. Free tours of the Kennedy Center are given by the Friends of the Kennedy Center from 10 a.m. to 5 p.m., Monday through Friday and 10 a.m. to 1 p.m., Saturday and Sunday. They depart from the parking plaza on Level A, and feature the Hall of States and Hall of Nations, the Center's main theaters, and dozens of paintings, sculptures, and other artworks given to the Center by foreign countries. For more information, call (202) 416-8340 (TTY 416-8524). Foggy Bottom Metro Station. (There is a free shuttle bus which takes visitors from the station to the center).
- The National Theater - 1321 Pennsylvania Ave, NW. Telephone: (202) 628-6161.
- Shakespeare Theatre at the Folger - 301 E. Capitol Street, SE. Telephone: (202) 547-3230; Box Office: (202) 544-7077.
- Source Theatre - 1835 14th Street, NW. Location: 1835 14th Street, NW (between S & T Streets, NW, 2 blocks from the U Street Cardoza Stop on Metro's Green Line). Telephone: (202) 462-1073.
- Studio Theater - 1333 P Street, NW. Box Office: (202) 332-3300.
- Warner Theater - Theatre Location: 13th & E Streets NW, Washington DC. Mailing Address: 1299 Pennsylvania Ave., Suite 111 Telephone: 202-783-4000. Metro: Metro Center (Red, Orange, and Blue lines) is located 1/2 block north of the Theatre.
- Washington Ballet - 3515 Wisconsin Ave, NW. Telephone: (202) 362-3606.
- Washington DC City Pages (Theater)
- Washington Performing Arts Society - 2000 L Street, NW, Suite 810. Telephone: (202) 833-9800.

through Saturday. Closed all Federal holidays. Admission: Free Tours: Regularly scheduled, no prior arrangement necessary. Metro: Capitol South or Union Station

- The John F. Kennedy Center for the Performing Arts - New Hampshire Avenue at Rock Creek Parkway, NW. Free tours of the Kennedy Center are given by the Friends of the Kennedy Center from 10 a.m. to 1 p.m. daily. Tours leave every 15 minutes. They depart from the parking plaza on Level A, and feature the Hall of States and Hall of Nations, the Center's main theaters, and dozens of paintings, sculptures, and other artworks given to the Center by foreign countries. For more information, call (202) 416-8340 (TTY 416-8524). Foggy Bottom Metro Station. (There is a free shuttle bus which takes visitors from the station to the center).
- The Library of Congress - Located on First Street SE between Independence Avenue and East Capitol Street, the Library of Congress houses more than 119 million items, including the papers of 23 presidents of the United States, Thomas Jefferson's rough draft of the Declaration of Independence and the earliest motion picture print.

The Thomas Jefferson Building was completed in 1897 and restored to its original splendor in 1997. Visitors can view the Main Reading Room with its magnificent domed ceiling from the Visitors' Gallery.

Adults over the age of 18 can utilize the Library's collections once they register as readers in room LM 140 of the Madison Building. Please note that the stacks are closed and that books are requested for use in the appropriate reading rooms.

There are guided tours daily, Monday through Saturday, at 11:30 am, 1:00, 2:30 and 4:00 pm. Spanish language tours are offered Tuesdays, Wednesdays and Thursdays at 12:30 pm. All tours start in the Visitors' Center in the Jefferson Building.

Researcher hours are not the same for all reading rooms. Be sure to call 707-6400 or visit our web site at www.loc.gov for complete information. For all other visitors, the hours of the Jefferson Building are Monday through Saturday from 10:00 am to 5:30 pm. The Library is closed on Sundays and federal holidays.

- The National Aquarium - 14th Street between Constitution Avenue & D Street, NW. Tanks filled with fish, frogs, alligators, sharks, etc.. Open daily from 9:00am to 5:00pm exception of Christmas. Admissions: Adults \$1.00, Senior Citizens & Children under 12 50 cents. Telephone: (202) 377-2825.
- The United States National Arboretum - 444 acres of trees, shrubs and assorted plants in the northeast section of the District of Columbia. Hours: 8:00am to 5:00pm, Monday through Friday. 10:00am to 5pm, Saturday and Sunday. Guide services for organized groups are available. Please make reservations for groups. Entrance: New York Avenue, NE. Metro: Stadium Armory on the blue or orange lines, then Bus number B-2, B-4, or B-5 to the intersection of Bladensburg Road and R Street, Walk east of R street 300 yards to the R street gate. Telephone: (202) 637-7000.
- The National Archives - 7th & Constitution Avenue, NW. Open Monday through Sunday 10:00 a.m. to 5:30 p.m. From April 1 until Labor Day the hours are 10:00 a.m. until 9:00p.m. Metro stop: Archives.
- The National Cathedral - It is located on Mount Saint Alban in Washington, D.C., which is one of the highest points in the city. Guided tours are given Monday through Saturday from 10:00 am to 3:15 pm and Sundays from 12:30 to 2:45 pm except during special events and services. There is a suggested donation of \$2.00 per adult and \$1.00 per child for tours. The grounds tour takes you

Appointment Center doors located next to the White House on 15th street between F and G streets, NW. Hours: Saturday morning, lasting 90 minutes. Admission: free. For Tour information or to make an advanced reservation call (202) 622-0896. For hearing impaired tours call (202) 622-0692. Metro: Metro Center.

- The White House - 1600 Pennsylvania Avenue, NW. Open Tuesday through Saturday, visitors are welcome from 10:00 am to 12 noon. The waiting area is not in effect between Labor Day & Memorial Day. This is a self-guided tour, however Tour Officers are stationed in each room to answer questions. Tickets are required for this tour during spring and summer months and can be acquired at no cost at the "Visitors Kiosk" on the Ellipse of the White House starting at 8:00 a.m. on the morning you wish to tour. Only one member of the family is required. A time will be issued for later in the day between 10am and noon. Guided Tours (reserved through Congressional offices) -- There are only ten Congressional Tour tickets issued per office per week. Congressional offices are not guaranteed tickets. They are given out on a first come, first serve basis. Our office is required to submit names a month in advance. Since the White House is occasionally closed for official events, it is recommended that visitors call in as far in advance as possible. White House Telephone: (202) 456-7041. For more information: (202) 456-2200. Metro: McPherson Square.
- Zoological Park - 3001 Connecticut Avenue, NW. 15: 6:00 a.m.-8:00 p.m., animal rooms open 10:00 a.m.-6:00 p.m.; September 16 to April 30: 6:00 a.m.-6:00 p.m., animal rooms open 10:00 - 4:30 p.m. unless otherwise posted. Phone (202) 673-4800 or 673-4717. Metro stop: Woodley Park

National Parkinson's Disease Organizations

Parkinson's Action Network

300 N. Lee St.
Suite 500
Alexandria, VA 22314
(800) 850-4726
(703) 518-0673 Fax
www.parkinsonsaction.org
info@parkinsonsaction.org

(Advocacy)

National Parkinson Foundation

1501 NW 9th Ave.
Miami, FL 33136
(800) 327-4545
(305) 243-4403 Fax
www.parkinson.org
mailbox@npf.med.miami.edu

(Research/ Support Groups)

The Michael J. Fox Foundation For Parkinson's Research

381 Park Ave. South
Suite 820
New York, NY 10016
(212) 213-3525
(212) 213-3523 Fax
www.michaeljfox.org

(Advocacy/ Research)

American Parkinson Disease Association

1250 Hylan Blvd.
Staten Island, NY 10305
(800) 223-2732
(718) 981-4399 Fax
www.apdaparkinson.com

(Research/ Referral Centers)

Parkinson's Disease Foundation

William Black Medical Research Building
Columbia-Presbyterian Medical Center
650 West 168th St.
New York, NY 10032
(212) 923-4700
(212) 923-4778 Fax
www.pdf.org
info@pdf.org

(Research)

The Parkinson's Institute

1170 Morse Ave.
Sunnyvale, CA 94089
(800) 786-2958
(408) 734-8522 Fax
www.parkinsonsinstitute.org

(Medical Questions/ Referrals)

Public Policy Forum 2002

Evaluation Form

Thank you for taking the time to fill out this evaluation form. It is a tool to help us in planning next year's Forum and making sure it is a success.

Please rate the following programs on a scale of 1-5 (1=poor, 5 = excellent):

Day 1

A. Grassroots Advocacy Program

The subject of the presentation:	1	2	3	4	5
The presenters:	1	2	3	4	5
The value of the information:	1	2	3	4	5
The handouts (if applicable)	1	2	3	4	5

B. Advocacy Training Sessions: Washington 101 (Undergraduate)

The subject of the presentation:	1	2	3	4	5
The presenters:	1	2	3	4	5
The value of the information:	1	2	3	4	5
The handouts (if applicable)	1	2	3	4	5

C. Advocacy Training Sessions: Expanding the Base (Graduate)

The subject of the presentation:	1	2	3	4	5
The presenters:	1	2	3	4	5
The value of the information:	1	2	3	4	5
The handouts (if applicable)	1	2	3	4	5

E. Neuroprotection Initiative at NINDS

The subject of the presentation:	1	2	3	4	5
The presenters:	1	2	3	4	5
The value of the information:	1	2	3	4	5
The handouts (if applicable)	1	2	3	4	5

Day 2

A. Federal Programs Funding Parkinson's Research

The subject of the presentation:	1	2	3	4	5
The presenters:	1	2	3	4	5
The value of the information:	1	2	3	4	5
The handouts (if applicable)	1	2	3	4	5

B. Update of Latest Drug Therapies from Pharmaceutical Companies

The subject of the presentation:	1	2	3	4	5
The presenters:	1	2	3	4	5
The value of the information:	1	2	3	4	5
The handouts (if applicable)	1	2	3	4	5

C. Washington 2002: What to Expect

The subject of the presentation:	1	2	3	4	5
The presenters:	1	2	3	4	5
The value of the information:	1	2	3	4	5
The handouts (if applicable)	1	2	3	4	5
The role-playing exercise:	1	2	3	4	5

Day 3

A. Scientific Briefing

The subject of the presentation:	1	2	3	4	5
The presenters:	1	2	3	4	5
The value of the information:	1	2	3	4	5
The handouts (if applicable)	1	2	3	4	5

B. Congressional Meetings

Scheduling/logistics of meetings:	1	2	3	4	5
Quality of Meetings:	1	2	3	4	5
Value of preparation for meetings:	1	2	3	4	5
Quality of handouts and talking	1	2	3	4	5
Points provided:					

PUBLIC POLICY FORUM 2002

Is this your first Public Policy Forum? Y N

Please rate your overall impression of the 2002 Public Policy Forum (1 = poor, 5 = excellent):

1 2 3 4 5

How do you rate the scheduling of the Forum?

1 2 3 4 5

What did you find *most* helpful or useful during the Forum?

What did you find *least* helpful or useful during the Forum?

Was the Yoga workshop helpful or interesting and do you have any suggestions for future Forums?

Do you now feel equipped to effectively communicate the Parkinson's agenda to your legislator?

Are there any skills that should have been taught or emphasized more?

Are you interested in the Grassroots Advocacy Program?

Has the Forum binder been helpful and easy to use?

Please give your suggestions and recommendations for future Public Policy Forums. (Please use the back of this sheet)

LOCAL MEDIA GUIDE

This document is designed to help Parkinson's advocates move beyond the beltway and build the case for increased funding for Parkinson's research on the local level by working with the local media. Below are three ways you, and other local advocates, can help to increase awareness about the need for a greater federal investment in Parkinson's research.

1. **ISSUE A NEWS RELEASE:** After you return from Washington, send a press release and photo of you, or your delegation, with your Member(s) of Congress to your local newspapers (see attached sample). Make sure you call the paper to ensure that they received the release and photograph. Smaller papers generally welcome these types of photos since they often don't have the staff to cover events themselves.
2. **LETTER-TO-THE-EDITOR:** Send a letter-to-the-editor of your local newspapers outlining the need for an increased federal investment in Parkinson's research (see attached sample).
3. **HOLD A LOCAL PARKINSON'S FORUM:** If possible, work with a group of Parkinson's advocates to organize a local forum on Parkinson's disease. Invite your Representative and/or Senator to participate in the event and invite the media to cover it.

Below is a suggested model for the event:

EVENT: Forum on Parkinson's disease that examines the state of current research and funding, as well as the outlook for a scientific breakthrough.

PARTICIPANTS: Local Parkinson's advocates
Member(s) of Congress
Local doctor or other Parkinson's expert
Scientist (if possible)

FORMAT: Panel discussion led by moderator (could be local advocate or Member of Congress). The event could begin with an overview of Parkinson's disease, by the doctor, and then evolve into a discussion about the current state of research, by the scientist (or Parkinson's advocate). The Member(s) of Congress could discuss the role of Congress and the status of federal funding.

LOCATION: Hospital
School
Other public meeting facility

AUDIENCE: Parkinson's advocates
Other local residents
Media

SECURING MEDIA COVERAGE: After the event is set-up you will need to take the following steps to secure media coverage of the forum:

Step 1 -- Media Advisory: Approximately one week before the forum you should fax a media advisory to all local media (daily and weekly newspapers, television stations, news radio and cable outlets) inviting them to cover the event. The advisory should include all of the logistical details about the event: who, what, where and when (see attached sample). Be sure to run the advisory by the Representative/Senator's press secretary to make sure they are comfortable with it.

Step 2 -- Follow-Up Calls: After the media advisory has been faxed to reporters, you should begin making follow-up calls to the media to encourage coverage of the event. Again, coordinate this with the press secretary so you complement each other's work, rather than unnecessarily duplicating efforts.

Step 3 -- Photos: Take photos during the event and send them, with a tag line describing the event, to weekly newspapers that were unable to cover it themselves.

SAMPLE PRESS RELEASE

FOR IMMEDIATE RELEASE
May XX, 2002

Contact: (Include name and phone number)

LOCAL PARKINSON'S ADVOCATE(S) TRAVEL TO WASHINGTON TO URGE INCREASED FEDERAL COMMITMENT FOR PARKINSON'S RESEARCH

(Insert city and state) – (Insert name) from (insert city/town) joined hundreds of Parkinson's advocates from across the nation in Washington, DC earlier this week to lobby Congress for an increased federal commitment for Parkinson's research. (Insert name) met with Rep./Sen. (insert name) to explain how additional federal funding could help scientists achieve a breakthrough for this devastating disease.

Scientists believe Parkinson's is the neurodegenerative disorder most likely to produce a breakthrough and that a cure is possible by the end of the decade – if the research dollars match the research opportunity.

"We sent a powerful message to Congress that without adequate federal funding for Parkinson's research, a cure may be unattainable," said (insert name). *Insert specifics about the meeting with your Member(s) of Congress.*

Parkinson's advocates participated in the Parkinson's Action Network's 2002 Public Policy Forum, in Washington, DC, May 19-21. The annual Forum is a unique opportunity for members of the Parkinson's community to come together to discuss the devastating nature of Parkinson's disease and the urgent need for increased federal funding to improve treatments and find a cure for Parkinson's with Members of Congress. Among other things, the three-day event includes a scientific briefing, a number of plenary sessions and meetings with Members of Congress.

In March 2000, the National Institutes of Health presented to Congress the Parkinson's Disease Research Agenda, which calls for an increase of nearly \$1 billion over five years for Parkinson's research. PAN is calling on Congress to fully fund the \$197.4 million increase over the baseline funding level for year three of the NIH's five-year Parkinson's Disease Research Agenda for FY 2003.

"The Parkinson's Disease Research Agenda provides Congress with a chance to close the funding gap for Parkinson's research by using NIH's own assessment of the current scientific opportunity," said (insert name). "Unfortunately, the Agenda has been severely under-funded by the NIH and will have a \$100 million shortfall in 2002 alone. It is critical to all who suffer from Parkinson's that Congress not let this kind of shortfall continue."

In addition, PAN is urging lawmakers to:

- Complete the 5-year doubling of the NIH's budget by providing an increase of \$3.7 billion in FY 2003.
- Support and fight for additional funding for the National Institute of Environmental Health Sciences (NIEHS); the DoD Neurotoxin Exposure Research Program; and the Department of Veterans Affairs (VA) Parkinson's Program.

- Support federal legislation and funding for stem cell research, Somatic Cell Nuclear Transfer (also known as therapeutic cloning) and other regenerative technologies.

PAN is the unified advocacy voice of the Parkinson's community, fighting for a cure within five years. Through education and interaction with the Parkinson's community, scientists, policy and opinion leaders, and the public at large, PAN advocates for increased and accelerated investment of public resources to ease the burden and bring a cure to the million Americans who suffer from Parkinson's. For more information, visit the PAN website at www.parkinsonsaction.org or call 800-850-4726.

###

SAMPLE LETTER-TO-THE-EDITOR

Dear Editor:

As one of the more than one million people who suffer from Parkinson's disease and a (insert number)-year resident of (insert town), I would like to share some exciting news about the potential for a breakthrough for this devastating disease.

Parkinson's disease is a movement disorder resulting from the degeneration and premature death of brain cells that produce dopamine. Symptoms include tremor, body rigidity, loss of balance, marked slowing of movement. Disability increases over years, and there is no cure at present.

However, scientists believe Parkinson's is the neurodegenerative disorder most likely to produce a breakthrough and that a cure is possible by the end of the decade – if the research dollars match the research opportunity.

I just returned from a trip to Washington, DC where I met with Rep./Sen. (insert name), about the need for a greater federal investment in Parkinson's disease. I joined hundreds of Parkinson's advocates from across the nation, who participated in the Parkinson's Action Network's (PAN) 2002 Public Policy Forum in Washington, DC, to lobby Congress for an increased federal commitment for Parkinson's research.

Specifically, we asked our Members of Congress to fully fund the National Institutes of Health's Parkinson's Disease Research Agenda, which calls for an increase of nearly \$1 billion over five years for Parkinson's research. To date, the Agenda has been severely under-funded by the NIH. The next step in carrying out this plan is an *increase* of \$197.4 million for year three of the Parkinson's Disease Research Agenda.

I am pleased to report that Rep./Sen (insert name) was receptive and promised to work to achieve this level of funding. However, it will take a sustained, national movement calling on Congress to fund this Research Agenda, to make our dream of a cure for Parkinson's a reality.

I urge everyone to take a few minutes to call your Members of Congress at 202-224-3121, and ask them to fully fund the Parkinson's Research Agenda. To find additional information about how to help in the effort to find a cure for Parkinson's, visit PAN's website at www.parkinsonsaction.org (or call 800-850-4726).

Sincerely,

(Name, address and phone number)

SAMPLE MEDIA ADVISORY

(Insert date)

Contact: (insert name and phone number)

REP./SEN. (INSERT NAME), LOCAL PARKINSON'S ADVOCATES, MEDICAL PROFESSIONALS TO HOST FORUM ON PARKINSON'S DISEASE

(Insert Town/County and State) – Rep./Sen. (insert name) will join local Parkinson's advocates, medical professionals and others at a forum on Parkinson's disease on (insert date and time) at (insert location). The forum will examine the state of current Parkinson's disease research and funding, as well as the outlook for a breakthrough.

Parkinson's disease is a movement disorder resulting from the degeneration and premature death of brain cells that produce dopamine. Symptoms include tremor, body rigidity, loss of balance, marked slowing of movement. Disability increases over years, and there is no cure at present.

Scientists believe Parkinson's is the neurodegenerative disorder most likely to produce a breakthrough and that a cure is possible by the end of the decade – if the research dollars match the research opportunity. However, a lack of adequate funding has impeded promising Parkinson's research. There have been too few clinical trials funded, too few papers published, too few resources spent on Parkinson's while the burden and cost of the disease in lost wages, health care and disability costs, and the very human toll it takes on individuals and their families is far too high.

WHO: Name of Member of Congress
 Name of Parkinson's advocates
 Name of doctors, researchers, scientist, others who will be participating in forum

WHAT: Forum on Parkinson's Disease that will examine the state of current Parkinson's disease research and funding, as well as the outlook for a breakthrough.

WHEN: Date and time

WHERE: Location and address

###

GUIDELINES FOR TALKING WITH THE MEDIA

Below are six essential guidelines that should be observed for every media interview opportunity. If practiced, they will become second nature and help you develop an internal, inherent process that will lead to improved media interviews. Following these guidelines will also leave you better prepared and more confident when speaking with the press.

1. Be Prepared

Never participate in a media interview without taking the time to prepare yourself mentally. Know the points you want to make and expect that there will be questions you may not be able to answer. Most importantly, know ahead of time what you want to communicate. Know the three to five points you want to make and write them down. This should be a checklist. If the reporter doesn't ask you questions that allow you to make these points, take the liberty of making them yourself.

2. Don't Assume the Reporter Already Knows Everything

While it's easy to assume that reporters who cover a beat that's relevant to your issue/cause know the details of what you're doing, background on the disease, etc., that's not necessarily the case. While some reporters (especially those with health-care trade publications) will be very knowledgeable about Parkinson's, others may be stretched too thin and therefore not as up-to-speed on the issue as you might think. Without talking down to the reporter, be sure to fully explain yourself.

3. Repeat Yourself

If you don't feel like you communicated something clearly, say it again. Repetition is the clearest way to drive home a point.

4. Be Honest

It's OK to admit to a reporter that you don't know the answer to a question. Rather than trying to answer a question that you are really unsure of and get it wrong, tell the reporter that you don't know the answer, but will find out and get back to them.

5. Offer to be a Resource

By engaging in an open and direct conversation with the reporter, you have already begun to establish a relationship. The reporter will appreciate your straightforward responses and the time you spend answering questions. At the end of the interview, be sure to let the reporter know you are available should they have additional questions or need information for a future story. Making yourself accessible and demonstrating your breadth of knowledge will help build an ongoing relationship and put you on the reporter's radar screen for future stories.

6. Relax and be Yourself

It's easy to feel intimidated or nervous when talking to the media. Try to relax and be yourself. If you are at ease and the reporter feels comfortable talking to you, it is more likely that you'll be called on again in the future.